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**Exploring the integration of self-management education in routine care of people with type 2 diabetes mellitus  
a qualitative study**

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King's College London

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**Exploring the Integration of Self-Management Education  
in Routine Care of People with Type 2 Diabetes Mellitus:  
A Qualitative Study**

THESIS

presented for the

DEGREE

OF

DOCTOR OF PHILOSOPHY

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## **Abstract**

**Background:** Self-management education supports people to live with diabetes and is a key element of diabetes care as recommended in national and international guidelines. However, in many countries, fewer than a third of people with type 2 diabetes mellitus (T2DM) participate in self-management education, and many do not receive adequate ongoing support following programme attendance. This unsatisfactory provision of support may suggest that self-management education programmes are insufficiently integrated into the routine care of people with T2DM.

**Aims:** This study explored integration in the context of self-management education programmes for people with T2DM in routine care to explain factors (components and mechanisms) that influence how people with T2DM and healthcare professionals (HCPs) experience and perceive the integration of such programmes at the patient, HCP and system levels.

**Methods:** Using a qualitative case study design, data of three self-management education programmes from a quality improvement initiative in diabetes care were collected and analysed. In total, 20 people with T2DM and 36 HCPs participated in semi-structured in-depth interviews; 88 hours of direct programme observation were undertaken; and 14 programme documents were reviewed. The data from the different sources were triangulated within a thematic narrative approach and synthesised across cases guided by the perspectives of complex adaptive systems.

**Results:** The study synthesis revealed components and mechanisms that describe the integration of self-management education into routine care. The identified components of integration were as follows: 1) person-centred care – the way HCPs support individual patients in engaging in self-management behaviour; 2) programme ethos – the approaches with which HCPs apply a theoretical programme framework in practice; 3) inter-professional work – the manner in which HCPs collaborate in delivering self-

management education; 4) communal resources – the local structures and processes by which a programme's context encourages self-management education; and 5) programme regulations – the recommendations and guidelines that standardise self-management education within a system. The mechanisms of integration related to the extent to which patients: 1) identified with their condition and activity; 2) experienced social support; 3) engaged in co-creating their interactions with HCPs; and 4) received self-management support by HCPs who congruently deliver such a care paradigm. The components and mechanisms of integration were observed to interact at and between the levels of people with T2DM, HCPs and the care system. These findings thus made it possible to conceptualise person-centred integrated self-management education as a form of dynamic relationships within interacting systems.

**Conclusion:** Understanding the context-specific nature of integration emphasises the need for a theory-driven approach. Dynamic relationships and interactions characterise the complexities associated with the integration of self-management education into routine care. Multiple strategies, which may collectively impact the behaviour of both people with T2DM and that of HCPs, are required to create the conditions for self-management behaviour to be developed and sustained in healthcare delivery. This knowledge may inform programme development and care delivery to better integrate self-management education into routine care. Follow-up research may investigate the potential benefits of programmes that incorporate person-centred care delivery with a whole-system approach of self-management support.

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## List of terms and abbreviations

CAS	Complex adaptive system(s)
CASP	Critical Appraisal Skills Programme
CDE	Certified diabetes educator
Cinahl	Current Index to Nursing and Allied Health Literature
CIS	Critical interpretive synthesis
COPD	Chronic obstructive pulmonary disease
DAS TPE	Diploma of Advanced Studies in Therapeutic Patient Education
DESMOND	Diabetes Education and Self-Management for On-going and Newly Diagnosed
DIAfit	Diabetes rehabilitation programme
DSN/DSNs	Diabetes specialist nurse(s)
ERIC	Education Resources Information Centre
EVIVO	Empowering and promoting self-management programme
GP/GPs	General practitioner(s)
HbA1c	Glycated haemoglobin
HCP/HCPs	Healthcare professional(s)
HMIC	Health Management Information Consortium

IDF	International Diabetes Federation
IT	Information technology
Medline	Medical literature analysis and retrieval system online
MeSH	Medical Subject Headings
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Co-operation and Development
PcD	Cantonal Diabetes Programme (Programme cantonal Diabète)
PCT	Pragmatic clinical trial
PRISM	Pictorial Representation of Illness and Self Measure
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
PsychINFO	Psychological Information Database
PwT2D	Person/people with type 2 diabetes
RCT	Randomised controlled trial
Scopus	Scopus Database
T1DM	Type 1 diabetes mellitus
T2DM	Type 2 diabetes mellitus
TE-AW	Therapeutic education awareness programme
TPE	Therapeutic patient education

UK	United Kingdom
USA	United States of America
WoS	Web of Science Database
WHO	World Health Organisation
X-Pert	Community-based self-management programme

## Chapter 1 Introduction

This first chapter provides the background for the study and introduces a conceptual framework and the study context. The chapter also outlines the researcher's personal position in the study and concludes by detailing the study's aim and objectives as well as an overview of the thesis chapters.

### 1.1 Background

Non-communicable diseases, such as diabetes, cardiovascular diseases, cancers and chronic obstructive pulmonary disease, cause major challenges not only for individuals and their families but also for society as a whole and for national healthcare systems as reported by the World Health Organisation (WHO 2013). The ill health and disability resulting from these conditions place a significant economic burden on healthcare systems, and these costs are increasing as prevalence of chronic diseases continues to rise. For example, the cost to treat diabetes is estimated to increase to US\$ 745 billion globally by the year 2030 (Bloom *et al.* 2011). In a recent report of the International Diabetes Federation (IDF), the global prevalence of diabetes was estimated to be over 415 million people, and that number continues to rise (Ogurtsova *et al.* 2017). Increased obesity and a longer life expectancy in most societies are the most significant factors driving the rising numbers of people living with diabetes (Lutz *et al.* 2008, IDF 2015).

There are two major forms of diabetes: type 2 diabetes mellitus (T2DM), which is a disease of insulin resistance and ineffective insulin secretion resulting in hyperglycaemia, and type 1 diabetes mellitus (T1DM), in which beta cells in the pancreas are destroyed as a result of an autoimmune process, leading to a loss of insulin production and resulting in hyperglycaemia (Skyler *et al.* 2017). The most common form of diabetes is T2DM, accounting for around 90% of all people living with diabetes (IDF 2015). The study focuses on T2DM based on the high incidence rate of the disease. The hyperglycaemia associated with T2DM and the often related metabolic dysfunction of

elevated lipids and hypertension can cause severe long-term health deficits, such as blindness, kidney disease and foot complications as well as myocardial, cerebral and vascular disease related to micro- and macrovascular damage (Gaede & Pedersen 2004, IDF 2015, WHO 2016). At the time of diagnosis, nearly half of people with T2DM already have signs of one of these long-term complications (IDF 2015).

These threats demand a comprehensive and integrated response from healthcare systems that provides appropriate management strategies to reduce hyperglycaemia, hyperlipidaemia and hypertension. The implementation of these strategies requires both lifestyle and pharmacological interventions. Because diabetes is a multi-systems disease, it needs an integrated approach for prevention, screening and management, thus involving a range of different disciplines and healthcare professionals (HCPs). The overall purpose of diabetes management is to prevent acute hypo- and hyperglycaemia and long-term complications. It is widely known that intensively lowering blood glucose to population-specific target ranges is an effective intervention for reducing the rates of diabetes complications (UK Prospective Diabetes Study Group 1998, Gray *et al.* 2002, Inzucchi *et al.* 2012, Zoungas *et al.* 2017). A crucial component of diabetes management is to provide educational support to patients to help them acquire and maintain effective self-management skills. This is because the impact of any intervention is mediated by the motivation and ability of the individual to manage and incorporate the behaviours (diet, exercise, glucose monitoring and in-take of medicines) necessary to realise the benefits of that intervention (Beaglehole *et al.* 2011, Bonita *et al.* 2013, WHO 2016). Therefore, it is essential that diabetes care systems incorporate self-management education and support strategies.

The overall purpose of self-management education and support is to prepare people with T2DM to make informed treatment decisions so they can better cope with the demands of living with diabetes and make changes in their behaviour to improve their health outcomes (IDF 2015, WHO 2016, Powers *et al.* 2017). The National Institute for Health

and Care Excellence (NICE 2017) recommends that the self-management practices in people with T2DM should be oriented towards significant lifestyle changes, such as increasing physical activity, reducing energy intake in their diet, monitoring their blood glucose levels and taking a range of oral and, in some cases, injectable medications, while psychosocially adapting to living with their chronic condition. Thus, developing effective self-management behaviour in this population is essential for reducing preventable complications and premature mortality and for easing financial pressure on healthcare systems.

A key strategy for supporting self-management behaviour is the use of patient education programmes (Lorig & Holman 2003, WHO 2016, Powers *et al.* 2017). These programmes have evolved over the last 60 years from a biomedical-centred approach of giving instructions to contextualising self-management education and providing ongoing support (Assal *et al.* 1997, Visser *et al.* 2001, Hoving *et al.* 2010, Funnell & Piatt 2017, Powers *et al.* 2017). Comprehensive self-management education is multifaceted; it engages people with diabetes in decision-making by providing them with the emotional, psychosocial and practical support they need to minimise the disease's impact on their health. This involves helping them acquire and use the technical knowledge required to manage their disease and recognising their physical, cognitive, emotional, social and spiritual needs as they handle their life issues within their own capabilities (WHO 1998, Duncan *et al.* 2009, Miles & Mezzich 2011, Entwistle & Watt 2013, Marrero *et al.* 2013, Cloninger *et al.* 2014, Powers *et al.* 2017).

However, self-management is shaped by the normative values that prevail in different communities, and the social and economic resources accessible to individuals may mediate the capacity of an individual to engage in self-management practices – particularly with respect to lifestyle obligations (Rogers *et al.* 2009a, Ellis *et al.* 2017). This introduces the potential for disparities and inequalities for individuals from lower socio-economic groups or for those who are bound by cultural norms that may override

their ability to activate or engage in self-management programmes (Rogers *et al.* 2009b, Gredig & Bartelsen-Raemy 2017). Hence, it is essential to keep in mind that not all individuals have the same economic and social resources with which to participate in self-management education on equal terms and to realise that this economic inequality may lead to health inequalities (Di Cesare *et al.* 2013, Devaux 2015). Therefore, it is important to consider these potential discrepancies in the study and to indicate the need to monitor socio-economic and cultural factors.

Moreover, attending to both the technical and the psychosocial aspects of diabetes can be challenging for both HCPs and patients. Healthcare professionals who often emphasise glucose management may prioritise the clinical and technical aspects of diabetes in a protocolled approach to treatments rather than adapt care to address the wider patients' needs within their agenda (Fix *et al.* 2018).

In addition, not attending to individual needs may contribute to the high rates of observed attrition in self-management education; more than half the participants withdrew from some programmes (Newman *et al.* 2004, Gucciardi 2008). Common reasons for this attrition include clashes between programme, work and family commitments; low perceived seriousness; and financial barriers to accessing medication and healthy food (Gucciardi *et al.* 2007, Winkley *et al.* 2015). Also, some patients may avoid engagement or the follow-up of self-management education because they have low self-esteem or perceive themselves to have failed for not achieving the recommended treatment goals (Gucciardi *et al.* 2008, Verevkina *et al.* 2014). Moreover, the reasons for disengagement may be related to a high level of disease burden, which is sometimes caused by multimorbidity or a low socio-economic position within an unsupportive social environment that undermines self-management behaviour and jeopardises the implementation of effective treatment (Teljeur *et al.* 2013, Weaver *et al.* 2014, Walker & Druss 2017).



Therefore, because patient behaviours in relation to lifestyle and self-management are central to achieving clinical outcomes, it is important for increasing retention to consider the socio-cultural context of patients in planning self-management support.

Furthermore, self-management education and support are often sporadically delivered at defined points by multiple diabetes specialists from different professional backgrounds; however, they are rarely implemented in a comprehensive way into the delivery of primary care, which is where most people with T2DM receive follow-up care (Snow *et al.* 2013, Kousoulis *et al.* 2014). In addition, the organisational and educational structures in primary care may challenge the use of self-management education by making competing demands of HCPs in their daily practice and by offering few incentives for HCPs to develop the additional skills they need for this care delivery (Forbes *et al.* 2011, Kennedy *et al.* 2014a). Hence, it is important to create a context for integrating self-management education into routine care.

Despite the presence of national and international recommendations on the importance of self-management education in diabetes treatment (WHO 2016, NICE 2017) and the fact that education programmes have been shown to be effective in improving biomedical, behavioural and psychosocial outcomes (Deakin *et al.* 2005, Sturt *et al.* 2008, Duke *et al.* 2009, Steinsbekk *et al.* 2012, Brunisholz *et al.* 2014), the overall adoption of such programmes is low in both specialist and primary care. For example, in the United Kingdom (UK), fewer than 10% of all people with T2DM who were offered the opportunity to participate in such programmes actually did so as reported in the National Diabetes Audit 2016-2017 (NDA 2018). A cross-national survey conducted in 17 countries showed that participation in self-management education varied considerably between regions – from as low as 20% in India to up to 85% in Canada (Nicolucci *et al.* 2013). In Switzerland, in the canton of Vaud, the cohort study of Zuercher *et al.* (2014) found that about 33% of people living with diabetes participated in self-management education. Moreover, as shown in a cross-country survey by Holt *et al.* (2013), many HCPs are inadequately trained in the delivery of comprehensive self-management

education, with over two thirds of the participating HCPs reporting deficiencies in their training and one third never receiving any training in self-management education at all. This suggests that self-management education is not sufficiently integrated into person-centred care delivery. This lack of fulfilled potential perpetuates the negative health outcomes of T2DM on individuals, their families and wider society.

While there is agreement on the need for person-centred care delivery, there is less consensus on how to implement it in everyday clinical practice (Gillespie *et al.* 2004, Legare *et al.* 2010). To address this disconnect, different initiatives have been developed to encourage the understanding and implementation of person-centred care in long-term conditions. Some of these initiatives use a theoretical framework to organise their interventions around person-centred care delivery. One example of this approach from the UK was the Year of Care programme (Year of Care 2011), which involved a whole-system approach to implementing Wagner's Chronic Care Model, which defines the important components required to facilitate self-management and to achieve improved patient care outcomes (Wagner 1998). The Year of Care programme adapted this model for use in primary care, using the following key strategies: preparing the HCPs and patients for a person-centred consultation, collaborative goal setting and action planning as part of a person-centred model of care (Coulter *et al.* 2013). The person-centred approach resulted in beneficial outcomes when combined with a change in care organisation and delivery to provide the supportive resources and care required to implement the programme in routine healthcare (Coulter *et al.* 2015).

Self-management education and support are multifaceted interventions influenced by the characteristics, activities and interactions of patients, HCPs and care systems – all of which potentially hinder the integration of a person-centred approach in routine care (Singer *et al.* 2011). For example, while person-centredness is promoted as a core element of care, in practice patients may lack the opportunity to voice their emotions and psychosocial concerns, and HCPs may be ambivalent about adopting a person-centred approach to care delivery in the limited time they have available for consultations, which

may also affect their communication (Greenfield 2014, Ignatowicz *et al.* 2014, Lawal *et al.* 2017). This relative disregard for person-centredness highlights the importance of creating conditions that support the implementation of person-centred care delivery and that foster helpful self-management behaviour in people with T2DM. Such conditions integrate a whole-of-system approach with the needs of people seeking and delivering care within multiple sectors of care delivery, as advocated in integrated care systems (WHO 2007, Ham & Walsh 2013, Cloninger *et al.* 2014).

Complex care situations demand a comprehensive and integrated response in order to optimise the care and treatment of people with T2DM (Bonita *et al.* 2013, WHO 2016). Integrated care has been described as a person-centred, continuous process based on shared responsibilities that are coordinated across care facilities and support systems (Singer *et al.* 2011, Cash-Gibson & Rosenmoller 2014). However, the process of integration is complex and difficult to describe because it is formed by multiple dynamic interactions at different levels in specific conditions (Goodwin 2013, Valentijn *et al.* 2013). This is relevant in the context of self-management education in routine care, where, in particular, dynamic relationships and interactions (which are not yet fully understood) may shape the outcome of the education.

Integration is a complex and multifaceted concept with no agreed upon definition in the field of healthcare. The concept has been associated with diverse objectives from several disciplinary and professional perspectives that relate to both integrated care processes and conceptual components considered in system theories (Kodner & Spreeuwenberg 2002, Armitage *et al.* 2009, Goodwin 2014). From a theoretical perspective in the context of healthcare delivery, the multiple components of integration relate to a vertical integration that describes the external linkages of care delivery, coordinating and building a whole-of-system approach, as well as a horizontal integration that internally joins multiple HCPs who collaborate and share a whole-of-care philosophy (Kodner 2009, Singer *et al.* 2011). A widely recognised definition of integration in healthcare delivery is

"a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors" (Kodner & Spreeuwenberg 2002, p.3).

However, comprehensive integration in a whole-of-system approach is challenged by the high level of fragmentation in care delivery with multiple services, HCPs and different underlying approaches to care within the current healthcare environment; this lack of connectivity may impede the implementation of an individualised system of patient support (Curry & Ham 2010, Shaw *et al.* 2011). To address these shortcomings, it is important to identify essential components of integration in the context of self-management education in order to understand their interactions and to develop strategies that may enhance programme delivery in routine care.

Routine care is shaped through the practices of patients and HCPs, resulting in dynamic interactions and relationships that express patterns in related systems, and understanding these interactions contributes to person-centred healthcare delivery (Sturmberg *et al.* 2014, Braithwaite *et al.* 2018). To study the complex and multifaceted concept of integration, it is useful to adopt a conceptual model that elicits the different components and mechanisms that facilitate integration. To do so, this study adopted the theory of complex adaptive systems (CAS), as it relates to interacting systems in a broad variety of contexts (Holland 1992). An investigation of healthcare through the perspective of CAS recognises that a linear step-by-step model is often not sufficient to implement evidence of healthcare delivery in routine care settings (Braithwaite *et al.* 2018, Greenhalgh & Papoutsis 2018). The main characteristics of CAS are their non-linear processes, emergent behaviour, co-evolution using simple rules and self-organisation (Benham-Hutchins & Clancy 2010, Ellis & Herbert 2011, Tsasis *et al.* 2012). These main features help develop an understanding of the interactions between an activated patient and a proactive HCP. Their relationship shapes self-management education, which is an

integrated part of the Chronic Care Model (Wagner 1998), and interacts along the axes of horizontal and vertical integration (Kodner & Spreeuwenberg 2002).

Complex adaptive systems have been widely used in multiple disciplines that face vague, uncertain and disordered situations (Begun & Kaissi 2004, Khan *et al.* 2018). In contrast to linear mechanistic systems that describe causality, CAS explain relationships and interactions that emerge from non-linear adaptive behaviour by identifying patterns in a particular context (Fraser & Greenhalgh 2001, Plsek & Greenhalgh 2001, Holland 2006, Edgren 2008). To understand the behaviour of systems, it is essential to identify and understand the nature and interrelatedness of their components (Plsek & Greenhalgh 2001, Plsek & Wilson 2001, Kannampallil *et al.* 2011, Paina & Peters 2012). For example, the CAS perspective was used by Cooper and Geyer (2009) to explore the transformative processes emerging from interactions in experiential learning that helped to identify participants' lived experiences and, in turn, to help HCPs adapt patient support accordingly. As positions change during interactions, both HCPs and people with T2DM may build a new context-specific relationship and move towards an altered form of stability (Cooper & Geyer 2007, Griffiths *et al.* 2010, Lacroix & Assal 2013). These relationships co-evolve during interactions, shape the process of consensus-building needed in shared decision-making and further the transfer of capabilities (Innes & Booher 1999, Innes *et al.* 2005).

Combining the whole-system approach of integrated care with the theory of CAS helps to explore the integration of self-management education from a comprehensive and systemic angle. Therefore, the CAS model was used in this study to develop a thorough understanding of dynamic interactions and relationships related to the integration of person-centred self-management education programmes into routine care. At the outset of this study, this theory informed the development of a provisional conceptual map of different areas pertaining to integration. This framework was then used to guide the study design and develop the model. The organisational framework provided a tool with which

to define properties of self-management education and key relational elements that connect the programme to patients, HCPs and system factors – as integration may manifest at these different levels.

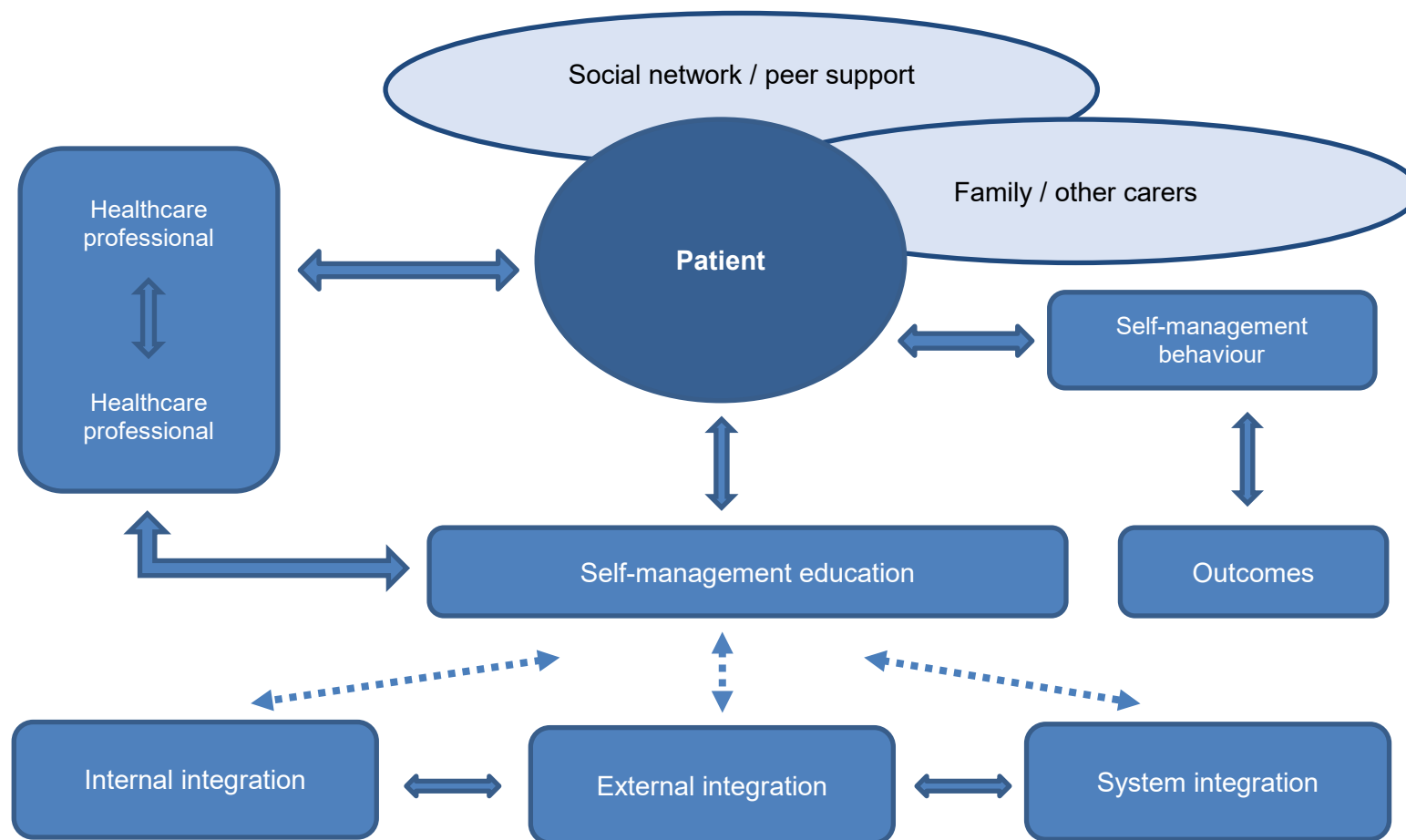
## **1.2 Conceptualising integration in self-management education**

A conceptual model demonstrates the complexity of integration in the context of self-management education in routine care. It is important to note that this initial model was designed purely as a framework. While it was used to guide the design of the study, it was left open to be modified by the data. The model is expressed schematically in Figure 1-1. The use of this model is further explicated in the ensuing chapters of the thesis.

The model illustrates the following systems, which may interact within self-management education: the patient system, the HCPs system and the care system (internal, external, and system integration). At the top centre of the model is the patient system interacting with family members and other carers and with their social network, including peer support. The patient's self-management behaviour affects his or her outcomes.

On the left side, the model presents HCPs interacting amongst themselves and building their own system that possibly influences their collaboration in care delivery – and, in turn, the patient's care experience. Self-management education and general interactions with HCPs may directly influence the patient's system.

The bottom of the model illustrates the care system in three sections that indirectly influence self-management education delivery, as depicted by the dotted lines. These sections are linked to internal integration that relates to multidisciplinary care delivery, external integration that connects self-management education to the delivery context and system integration that represents the care system in which self-management education is provided. These sections may also directly interact with each other.



**Figure 1-1** Conceptual model of integrated self-management education

### 1.3 Study context

The study explored the integration of self-management education within a recently developed comprehensive care improvement strategy (Hagon-Traub *et al.* 2013) in one region (canton) in the French-speaking part of Switzerland, which has almost 800,000 inhabitants (Statistique Vaud 2016). The Public Health Service of the canton of Vaud mandates the Cantonal Diabetes Programme (PcD) in order to improve care for people with diabetes (Hagon-Traub *et al.* 2010). The programme is located at the Cantonal Diabetes Association, which is also a patient organisation (Hagon-Traub *et al.* 2013, Meyer 2016).

The Cantonal Diabetes Programme aims to ease the impact of diabetes on the population by improving the quality of diabetes care. It was developed based on identified population needs together with HCPs, patients, academic and professional institutions (Lauvergeon *et al.* 2012, Hagon-Traub *et al.* 2013, Peytremann-Bridevaux *et al.* 2017). These combined top-down and bottom-up approaches involved stakeholders, HCPs and patients in the process to develop a comprehensive programme of diabetes care integrated into routine care delivery (Peytremann-Bridevaux *et al.* 2017). An overview of the approaches used in the PcD is provided in Appendix I.

Based on Wagner's Chronic Care Model (1998), PcD revolves around five focus areas: 1) self-management and patient support – to empower patients by reinforcing their health competences; 2) health promotion and primary and secondary prevention – to encourage physical activity and a healthy diet; 3) improvement in management – to systematise interdisciplinary and coordinated management processes based on recommendations for good clinical practice; 4) training for HCPs – to strengthen their skills and improve interdisciplinary management; and 5) communication – to improve the organisation of care through communication tools and measures (Hagon-Traub *et al.* 2010). The programme projects were piloted and evaluated: Between 2010 and 2015, more than 85



projects were initiated (Programme cantonal Diabète 2016a) and of those, over 40 implemented (see Appendix II and Appendix III).

People living with T2DM in this cantonal context generally have unrestricted access to diabetes care, and their follow-up care is mostly conducted in general practice (Bovier *et al.* 2007, Peytremann-Bridevaux *et al.* 2013). However, prior to the programme, the self-management education provided was not clearly defined, nor was it based on the principle of proactively engaging people with chronic conditions by systematically using person-centred models of self-management support. These deficits were reflected in a local study which identified the following facets of care as lacking or underused: coordination and systematic follow-up, integration of multidisciplinary care delivery to address the patients' multiple needs, and self-management education and support (Peytremann-Bridevaux *et al.* 2013).

The broader context of this study is the healthcare system of Switzerland, which has universal healthcare coverage ensured through mandatory health insurance and subsidies for people with low incomes (De Pietro *et al.* 2015). The Swiss direct democratic system shapes the regulatory framework of sharing decision-making powers and commissioning at different levels: the federal, cantonal and communal governments (De Pietro *et al.* 2015). Civil societies such as associations of healthcare professionals and health insurers and the Swiss population also play a role in regulating healthcare as they have the power to veto or demand reform provision through public referenda (see Appendix IV). Several reform initiatives and population votes in relation to healthcare have been on the political agenda in the last 25 years, but building a national consensus on healthcare in Switzerland remains challenging, as a broad agreement of the main stakeholders is required (Cheng 2010, De Pietro *et al.* 2015, Peytremann-Bridevaux *et al.* 2017).

The decentralised organisation of healthcare at the cantonal level increases fragmentation into 26 separate cantonal systems, but it also enables the provision of

healthcare to be adapted to the local population's needs, which is especially useful in a multi-linguistic country (Mossialos *et al.* 2016, Schussele Fillietaz *et al.* 2018). The performance of the Swiss healthcare system is characterised by a generally long life expectancy and high levels of patient satisfaction – both of which come at considerable costs – according to the joint report of the Organisation for Economic Co-operation and Development and the World Health Organisation (OECD 2011).

The Cantonal Diabetes Programme – with its comprehensive approach to healthcare delivery – provides a good context in which to study integration in relation to self-management education. The programme also reflects the parameters outlined in the conceptual model presented in the previous section. While the cantonal programme is specific to one region of Switzerland, it is modelled on current approaches to diabetes education which have been adopted elsewhere in the world. Therefore, this study has the potential to generate transferable insights into the nature of integration within diabetes self-management education.

#### **1.4 Researcher's personal role in the study**

I first became interested in this research project when practising on a multidisciplinary team as a diabetes specialist nurse, a role in which I consulted with many people living with T2DM from diverse social backgrounds. People engage in their diabetes treatment differently and in how they manage diabetes in the short, mid and long term, which was evident from my clinical practice. Although self-management education and support was provided to the people referred to the clinic, too often their engagement in self-management behaviours did not continue for various reasons after they were referred back to their primary care providers.

My professional network, established over many years of work experience in various fields and as co-president of the national organisation of diabetes specialist nurses (a subgroup of the Swiss nursing association), facilitated contact with other HCPs. The professional exchange with colleagues from other areas indicated that potential disengagement and disconnected service delivery were common occurrences in healthcare, though the available resources and collaboration varied according to region. My personal interest and professional understanding of chronic disease and self-management played an important role in the design of the study as I had the opportunity to be involved in the national discussion regarding care delivery and self-management education (Colque *et al.* 2014). Thus, my personal experiences encouraged me to engage in this in-depth exploration of factors that influence the integration of self-management education in the care of people with T2DM.

In the study, I acknowledge my role as someone conducting research rather than functioning as a clinician, while I recognise that my previous understanding nurtured this research project. I use the personal pronoun "I" only when I provide reflective comments. My doctoral research was performed independently under the direction of my supervisors and local mentors, and it was supported by an educational grant from the Nursing Science Foundation Switzerland.

## **1.5 Study aim, research questions and objectives**

In light of the rationale, context and conceptual platform outlined above, the aim of this study was to explore integration in the context of self-management education for people with T2DM in routine care. The study addressed the following research questions:

- How does integration manifest in different components of programmes of self-management education (considering programme structures, context and participant experiences)?
- What mechanisms at the patient, healthcare professional and system levels shape the expression of integration in the delivery of the self-management education programme?

The study objectives were as follows:

- to explore the experiences and perceptions of integration among people with T2DM and healthcare professionals in the context of self-management education;
- to identify components and mechanisms of integration in person-centred self-management education;
- to develop a theoretical model of person-centred integrated self-management education.

With this new knowledge, strategies may be developed to advance care delivery, the potential benefits of a self-management programme may be maximised, and patient outcomes may be improved.

## **1.6 Overview of the thesis**

The first three chapters of this thesis provide the background and context to the study of self-management integration and describe the theoretical frameworks used to support the inquiry, building on the concepts outlined in this chapter. They proceed as follows:

- Chapter 1: Introduction and background of the study
- Chapter 2: Systematic literature review and presentation of the theoretical model of how integration relates to self-management education
- Chapter 3: Description and rationale for using the case study research methodology with a thematic narrative-based approach in the empirical study

Four chapters present the study's findings. Chapter 4 describes in detail the study participants, settings and context. Chapters 5 to 7 describe the within-case analysis of each case, and Chapter 8 presents the cross-case analysis:

- Chapter 4: Description of self-management education programmes in setting and context, including demographic characteristics
- Chapter 5: Case A – Reinforcing patients' capabilities to self-manage everyday activities
- Chapter 6: Case B – Increasing level of physical activities and understanding of disease
- Chapter 7: Case C – Reflective practice to build therapeutic relationships and care networks
- Chapter 8: The cross-case analysis and the presentation of the synthesis in relation to the theoretical model

The final chapter presents the discussion and conclusions of the study:

- Chapter 9: Discussion and synthesis of the major study findings, including strengths and limitations, followed by implications for practice and future research and dissemination of the study findings

## **1.7 Summary**

The prevalence of T2DM, a global issue with multiple high-cost complications, is increasing. To prevent these complications, people with T2DM need to be enabled to develop a range of self-management behaviours. A key strategy to achieve this goal is the use of self-management education programmes. Recently, more person-centred approaches that emphasise psychosocial strategies have been used to promote behaviour change because didactic programmes often fail to engage patients in adopting self-management behaviours. Moreover, educational programmes are frequently insufficiently integrated into the socio-cultural context and the care delivery system, thus contributing to suboptimal outcomes. Integration is a complex construct with varying definitions, and it is influenced by the activities of and interactions between patients, HCPs and the healthcare system. Therefore, it is important to understand the components and mechanisms that contribute to the integration of self-management education into routine care. Considering the perspectives of CAS theory, this study explores integration within self-management education at the patient, HCP and system levels within the context of a major new programme of diabetes care in a region of Switzerland. As a result of that exploration, novel insights are developed regarding the nature of integration, and these insights may inform strategies that enhance the integration of diabetes self-management education programmes into routine care.

This is the first study to explore integrating self-management education into routine care for people with T2DM from a CAS perspective. Within this context, it is also the first to explicitly consider how self-management education programmes relate to the experiences of both patients and the HCPs who deliver such care.

The next chapter presents a systematic literature review that identifies different components of how integration relates to self-management education. It also investigates how patients and HCPs perceive and experience such care.

## **Chapter 2 Literature review**

This chapter presents a systematic review of the research literature in order to construct a theoretical framework that develops an understanding of integration within the context of self-management education. The sections below describe the methodology and methods used in the systematic literature review as well as the search results and synthesis of the findings. The chapter closes with a discussion and conclusion.

### **2.1 Introduction**

This systematic review conceptualises integration from multiple perspectives using a qualitative synthesis to generate theory (Dixon-Woods *et al.* 2006, Pluye & Hong 2014).

The literature review addresses the following research questions:

- How is integration manifest in self-management education programmes for people with type 2 diabetes delivered by interdisciplinary healthcare teams?
- What do the perspectives and experiences of people with type 2 diabetes and healthcare professionals reveal about integration in the context of self-management education programmes in routine care?

### **2.2 Methods**

To develop the conceptual framing of how integration relates to self-management education from multiple perspectives and incorporating a diverse body of literature, a critical interpretive synthesis (CIS) was considered an appropriate method (Dixon-Woods *et al.* 2006, Flemming 2010, Reynolds *et al.* 2015). A CIS synthesises the findings from both qualitative and quantitative studies, thus providing a deeper understanding of a field of research than would be possible with the mere aggregation of evidence (Whittemore & Knafl 2005, Dixon-Woods *et al.* 2006). This approach of translating quantitative and qualitative studies into new theoretical concepts is in concordance with the perspectives described in CAS, where the dynamic relationships

and interactions of a system amount to more than the sum of the parts (Paina & Peters 2012).

### **2.2.1 Methodological approach**

Dixon-Woods *et al.* (2006) developed CIS to generate theory from various types of literature, using an interpretive approach to synthesise the evidence. This transformation-based approach was modified from meta-ethnography (Noblit & Hare 1988, Pope *et al.* 2007) and grounded theory (Glaser & Strauss 1999). Following the approach of Dixon-Woods *et al.* (2006), in both qualitative and quantitative studies, themes relating to integration were extracted and critically examined across studies in terms of similarities and differences. This approach made it possible to build a line of argument that theoretically explains integration in the context of diabetes self-management education.

In the quantitative studies, concepts relating to integration were identified and coded in the self-management interventions described in the individual studies. In the qualitative studies, the themes were directly imported from the source studies. When the thematic coding of both study types was completed, the collective codes were transformed into one another to conceptualise how integration relates to self-management education.

### **2.2.2 Search strategy**

An integrated search strategy was conducted in two phases with several preliminary searches in order to explore the breadth of relevant literature and refine the search terms. Because the literature was potentially very broad, it was discussed with supervisors which conditions would be most relevant to informing the conceptualisation of how integration relates to self-management education. Interventions involving an interdisciplinary healthcare team either working in the same setting or different settings and providing self-management education to people with type 2 diabetes were



considered to be most suitable. Thus, five facets for the search were identified in order to address the research questions:

- **Integration:** systems of standard healthcare that combine the planned delivery of structured self-management education by interdisciplinary teams who work either in the same setting or in different settings;
- **Self-management:** patients' self-care behaviours that relate to participating in their own healthcare;
- **Education:** structured programmes of teaching or training patients concerning their own health needs;
- **Interdisciplinary team:** multidisciplinary team members with specific responsibilities in delivering coordinated patient care;
- **Type 2 diabetes:** a chronic disease characterised by insulin resistance, glucose intolerance and hyperglycaemia independent of the disease treatment.

Scoping reviews were then undertaken in order to refine the search terms used for each string. A range of electronic databases and “grey” literature resources were identified to provide access to literature from multiple disciplines and different study types. The search strategies were discussed with a librarian and adapted for each database, and search strings for each facet mentioned above were constructed with multiple terms and synonyms. Truncation was applied to control for spelling variations. The databases presented below were searched comprehensively for relevant literature, using both the Medical Subject Headings (MeSH) and free-text keywords that referred to type 2 diabetes, integration, self-management, education and interdisciplinary teams. The strings were searched individually first and then in combination. Validated methodological filters for capturing qualitative and quantitative studies were identified by consulting a librarian and different guidelines (Flemming & Briggs 2007, McKibbin *et al.* 2009). The syntax of the search terms was adapted for each database. The citations were exported to Endnote (version x7), and all duplicates were removed. The sets of search terms were applied in the databases shown in Table 2-1.

**Table 2-1** Databases searched in the literature review from 2004 to 2014

Database	Literature covered	Reasons for searching
Medical Literature Analysis and Retrieval System Online (Medline)	Clinical medicine, biomedical, nursing, healthcare delivery, nutrition, psychology, social science and education	Most widely used database for information retrieval in biomedicine and health
Health Management Information Consortium (HMIC)	Health and social care management, UK-focused records	Related to King's Fund database and Department of Health's DH-data, including grey literature
Psychological Information Database (PsychINFO)	Psychology and psychiatry, including education, medicine and nursing with references to theses and reports	Related to psychology, education and nursing, including grey literature
Current Index to Nursing and Allied Health Literature (Cinahl)	Nursing and allied health	Most widely used database for nursing and allied health disciplines
Education Resources Information Centre (ERIC)	Education and educational research	Most widely used database for literature in education
Scopus	Life science, health sciences, physical sciences and social sciences	Related to peer-reviewed research literature
Web of Science (WoS)	Social sciences, arts and humanities	Related to citation index report
Cochrane Central Register of Controlled Trials	Controlled trials in healthcare	Related to evidence-based practice

While in some systematic review methodologies studies are selected based solely on methodological quality, the purpose of interpretive synthesis is to include papers based on their conceptual quality, provided their content is relevant to the review questions (Dixon-Woods *et al.* 2006). Hence, studies were chosen for inclusion based not exclusively on their methodological quality but rather on their ability to address the research questions. All studies identified in the initial search were first assessed for their relevance to conceptualising how integration relates to self-management by reviewing their titles, abstracts and descriptor/MeSH terms. At this stage, studies were rated as “probably relevant”, “of uncertain relevance” or “irrelevant” using the inclusion/exclusion criteria listed in section 2.2.4. The full texts of studies that were rated as “probably

relevant” or “of uncertain relevance” were further assessed. The electronic search was supplemented by a manual search for the cited references of all potentially relevant studies.

### **2.2.3 Searching other resources**

After relevant studies were selected from the electronic literature database search, a selective search of relevant organisations was conducted to identify additional evidence that might be relevant for the purpose of this research. In conducting complex reviews, it has been shown that supplemental approaches may be helpful in finding additional papers (Greenhalgh & Peacock 2005, Dixon-Woods *et al.* 2006). Therefore, the websites of relevant international organisations were searched, and colleagues with an interest in the field were asked for suggestions.

### **2.2.4 Eligibility criteria**

The inclusion and exclusion criteria for the literature review are presented below.

#### **2.2.4.1 Inclusion criteria**

##### *Types of studies*

Two groups of studies were considered as related but discrete areas:

- 1) qualitative studies, and
- 2) quantitative studies with a prospective, interventional study design.

Studies were deemed relevant if they were conducted in the context of a programme of self-management education and had two or more of the following characteristics:

- delivered by a multidisciplinary team (e.g. general practitioner, diabetologist, diabetes specialist nurse, dietician, allied HCP, peer educator);
- and demonstrated a continuous educational route in one setting (e.g. hospital, outpatient clinic, medical home, general practice)

or in a virtual network with evident linkages to a community or primary/secondary care (e.g. co-consultation) – or with ongoing support (e.g. in person, by telephone, online or peer);

- and clearly described content, method, mode, deliverer, receiver and context.

#### *Types of articles*

Articles that related to original primary studies of self-management education were included in the review.

#### *Study population*

Studies of adults ( $\geq 18$  years of age) with diagnosed type 2 diabetes participating in self-management education or of HCPs delivering self-management education to these participants were included.

#### *Language of publication*

There was no restriction on the language of the articles. Studies published in languages other than English, German and French were considered if an English abstract was provided.

#### *Date of publication*

Studies published within the last 10 years were included because the intention was to address current practices of self-management education.

#### **2.2.4.2 Exclusion criteria**

Studies were excluded if they did not report on original primary data or contribute to the conceptualisation of integration in the context of self-management education. Studies without an abstract or accessibility to the full text were excluded because they did not provide enough information to assess whether they contained components related to the integration of self-management education.

### **2.2.5 Data extraction**

Two data collection tools were developed to ensure a standard approach in the extraction of information from the articles selected: author, year, country, study design, purpose/aim, sample setting, participants (*i.e.* receiver of intervention) and HCPs (*i.e.* deliverer of intervention) were extracted from both quantitative and qualitative studies. In addition, extraction from the quantitative studies included: intervention, theoretical framework of intervention, control, follow-up, primary outcome and, if available, patient-reported outcomes (see Appendix V). Extraction from the qualitative studies included additionally: data collection methods, ethical approval, participant eligibility criteria, sampling method, recruitment context, data analysis, and identified themes and sub-themes from the source study (see Appendix VI).

### **2.2.6 Quality assessment**

The qualitative and quantitative studies were appraised with the Critical Appraisal Skills Programme (2014), which provides checklists for qualitative research and randomised controlled trials (RCT), awarding them a score of either 0 or 1 for research design, for methods used for data collection and analysis and for the research value of the study. The likely relevance of a paper as it pertained to the concept of integration was initially appraised by applying five criteria (Annandale *et al.* 2007): 1) clearly stated aim and objectives of the research; 2) clearly specified research design, appropriate for the aims and objectives of the research; 3) researchers provided a clear account of the process by which their findings were produced; 4) enough data displayed to support their interpretations and conclusions; and 5) appropriate method of analysis and adequate explication.

### **2.2.7 Data analysis and synthesis approach**

A qualitative synthesis of findings from both qualitative and quantitative studies with a critical interpretive approach in a convergent, mixed-studies review design is suited to

address complementary but discrete sets of research questions (Dixon-Woods *et al.* 2006, Pluye & Hong 2014). Synthesising heterogeneous data from a range of disciplines and paradigms to integrate a set of concepts and themes has been done before, and the synthesis may develop around a core concept to define theory (Dixon-Woods *et al.* 2006, Boyko *et al.* 2012, Kangasniemi *et al.* 2014). For this review, the synthesis was conducted around the core construct of integration in relation to self-management education.

### **2.3 Data synthesis**

The CIS approach was used as a transforming technique for qualitative and quantitative studies (Dixon-Woods *et al.* 2006). This synthesis consists of four overlapping steps (Dixon-Woods *et al.* 2006, Boyko *et al.* 2012), detailed below:

- *Step 1: Understanding the paper in relation to itself and identifying themes*

In this initial phase, a paper was read and re-read to develop an understanding of its position and context and to consider whether the content was relevant to the research questions. In keeping with the CIS, this phase emphasised the relevance of a given study to the conceptualisation of integration, rather than focusing on its methodological approach. The themes identified from the coded source studies were analysed for their contribution to capture ways in which the literature described factors of integration among the data. The concepts emerged directly from the themes identified in the quantitative studies and were complemented with similarly coded themes identified in the qualitative studies.

- *Step 2: Translating studies into one another*

The themes derived from the full-text version of the studies were compared to the data in each of the papers to further specify the conceptualisation of integration and to examine the constructs across studies in terms of similarities and differences. The themes identified in the studies were translated from one study into another in order to develop a reduced account of the content and context of all studies included. The

concepts were derived from the most influential themes in the source studies and identify how they relate to each other.

- *Step 3: Synthesising translations*

The translations of studies were compared to further determine whether the concepts represented were incorporated in other accounts. Similar concepts were then grouped together and examined for patterns across the studies. The concepts emerged directly from the evidence identified in the synthesis, and, as a result, they express a transformed conceptual form, which in the CIS approach is called synthetic constructs. In the context of this research, the synthetic constructs characterise the components of integration in relation to self-management education and furthers the development of the theoretical framework.

- *Step 4: Expressing the synthesis*

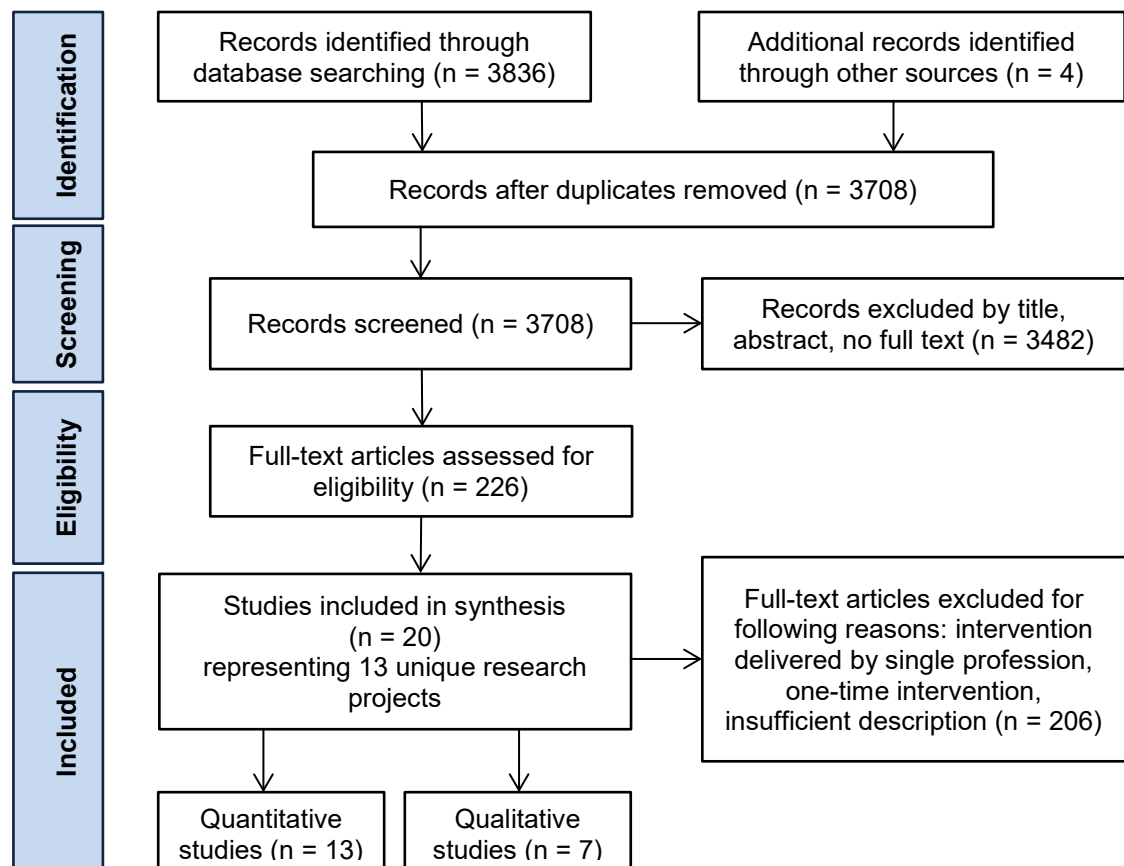
In developing the synthesising argument, the evidence from across the studies was integrated into a theoretical framework. The synthesising argument links the synthetic constructs to the themes of the source studies. The theoretical framework comprises organised evidence from the literature and contains an interpretation of the concepts expressed and the deficiencies identified in the studies. The synthesis integrates the components of integration with the evidence from the source studies and interprets their interactions in the context of self-management education.

The review examined how integration has been represented, constructed and reported in the literature. First, a tabulative analysis of studies was conducted to identify key concepts pertaining to integration. This was done by examining the detailed intervention in the studies to describe how integration relates to self-management education. Second, a matrix-based tabulative synthesis was used to display the constructs that emerged from the evidence of qualitative and quantitative studies. Although this approach was originally only used for qualitative studies (Miles & Huberman 1994), it has recently been used as an organising framework to integrate qualitative and quantitative studies (Dixon-Woods *et al.* 2006, Flemming 2010).

## 2.4 Search results

### 2.4.1 Overview of search results

The search of the electronic bibliographic databases identified 3708 studies for screening after excluding the 132 duplicates and adding four additional records identified through other sources. Full texts were obtained for 226 studies, from which 206 articles were further excluded for the following reasons: 1) intervention was uni-professional; 2) single occurrence of intervention without organisational or professional context for continuity; or 3) insufficient description of the educational intervention. From the database searches, 16 results were found to be relevant, and a further four studies were identified from additional resources. Of those 20 studies, 13 were quantitative with an interventional study design, and seven were qualitative. These 20 articles in total represented 13 unique research projects. The flow chart in Figure 2-1 illustrates the study selection process:



**Figure 2-1** Study selection using modified PRISMA flow chart (Moher *et al.* 2009)



#### 2.4.2 Characteristics of relevant studies

The 20 studies included were distributed across 9 countries: Australia (n = 2), Belgium (n = 2), France (n = 2), Italy (n = 1), Norway (n = 2), South Korea (n = 1), Sweden (n = 3), the UK (n = 3), and the USA (n = 4). The seven qualitative studies were embedded in an evaluation study and originated from Australia (Hepworth *et al.* 2013, Russell *et al.* 2013), Belgium (Goderis *et al.* 2009, Goderis *et al.* 2010), France (Balcou-Debussche & Debussche 2009, Debussche *et al.* 2012), Norway (Rygg *et al.* 2010, Rygg *et al.* 2012), Sweden (Adolfsson *et al.* 2007, Adolfsson *et al.* 2008), the UK (Carey *et al.* 2014, Mandalia *et al.* 2014) and the USA (Glasgow *et al.* 2012a, Glasgow *et al.* 2012b). The quantitative studies were conducted in Italy (Trento *et al.* 2010), South Korea (Ko *et al.* 2007), Sweden (Sarkadi & Rosenqvist 2004), the UK (Deakin *et al.* 2006) and the USA (Piatt *et al.* 2006, Katon *et al.* 2010).

The characteristics of the study design, programme context and participants, together with the key concepts and themes related to integration, are presented in Table 2-2 (quantitative studies) and Table 2-3 (qualitative studies). Consistent with the CIS approach, the main criterion was conceptual relevance rather than methodological rigour (Dixon-Woods *et al.* 2006). The qualitative studies generally had clear research aims and an adequately described methodology, although the relationship between researcher and participants was not always made explicit. The quality score of the quantitative studies varied from high to medium to low. While the methodological quality of one study was poor, it was highly relevant to the conceptualisation of integration, although the samples might have been biased through the sampling process (Russell *et al.* 2013). However, in CIS conceptual relevance is more important than methodological rigour and therefore, all selected studies were included in the review.

**Table 2-2** Summary of quantitative studies included in the review

Author, year, country	Study design	Purpose/aim	Main professionals and theoretical framework	Intervention	Participants and location	Key concepts/themes
Adolfsson <i>et al.</i> (2007), Sweden	Randomised controlled trial	Evaluate the impact of empowerment group education in primary care	GP and diabetes specialist nurse; based on empowerment	Five 2.5-hour group sessions with one follow-up session using reflection and feedback among participants  Joint HCPs training (5 days in total): simulation; workshop understanding empowerment, motivation and learning principles; practising in four supervised pilot group sessions; and follow-up-meetings	PwT2D in seven primary care centres in Central Sweden (n = 101)	<ul style="list-style-type: none"> <li>• Reflective peer discussion</li> <li>• HCPs understanding of theoretical concepts and delivery mode</li> </ul>
Carey <i>et al.</i> (2014), UK	Non-randomised controlled trial	Evaluate the delivery of the DESMOND diabetes self-management education programme by paired professional and lay educators	Lay educator and HCP; based on self-regulation theory, dual process theory, self-determination theory and social-cognitive theory	Six-hour structured group self-management education programme for PwT2D, delivered either over 1 day or 2 half days  Lay educator training (6 days): preparation day; standard DESMOND educator training, joint practice days and training of lay and HCP educator; additional day for lay educator; site visits and quality assessment	PwT2D in four primary care organisations across England and Scotland (n = 260)	<ul style="list-style-type: none"> <li>• Equal roles of HCPs and peer educators in interactions</li> <li>• Joint training of HCPs and laypeople in programme delivery</li> </ul>
Deakin <i>et al.</i> (2006), UK	Pragmatic clinical trial	Evaluate a group-based, peer-led self-management programme (X-PERT) in community venues	HCP, peer educator and an (Urdu-speaking) cultural translator in some sessions; based on empowerment (problem-solving strategies)	Six 2-hour weekly group sessions separately conducted for Urdu-speaking South Asian participants with the support of a translator.  Joint training: not reported  Programme contains written curriculum, visual aids, a “train the trainers” course, evaluation scheme and quality assurance programme	PwT2D with Caucasian and South Asian backgrounds in primary care and community venues in North West England (n = 314)	<ul style="list-style-type: none"> <li>• Interactions with peers</li> <li>• Peer support by trained layperson</li> <li>• Local access (community)</li> <li>• Linguistic and cultural programme adaptation</li> </ul>

Author, year, country	Study design	Purpose/aim	Main professionals and theoretical framework	Intervention	Participants and location	Key concepts/themes
Debussche <i>et al.</i> (2012), France	Randomised controlled trial	Evaluate quarterly outpatient counselling visits by nurses and dietitians following in-hospital educational sessions	Diabetes specialist nurse and dietitian; based on problem-solving strategies	Quarterly lifestyle support in outpatient clinic from Creole-speaking nurses and dietitians after intensive in-hospital group education  Initial educational cycle: interactive lectures and focus group discussions (1–2 hours) on six diabetes-related topics as well as physical activity and cooking workshops by a multidisciplinary healthcare team  Postal and telephone reminder	PwT2D recruited from two endocrinology departments of the Regional Hospital of Reunion Island (n = 398)	<ul style="list-style-type: none"> <li>• Linguistic and cultural programme adaptation</li> <li>• Collaboration of multidisciplinary diabetes care team</li> <li>• Regular follow-up (by multidisciplinary team)</li> <li>• Recall system</li> </ul>
Glasgow <i>et al.</i> (2012b), USA	Pragmatic clinical trial	Evaluate internet-based self-management programme with or without additional live support	GP, diabetes educator, dietitian, trained bilingual staff; based on social-cognitive theory and social-ecological model	Web access to an interactive self-management programme (in Spanish and English) providing goal setting with automated feedback and prompts as well as information on community resources and a moderated forum  Additional support: social support with two personal follow-up calls and three 2-hour group sessions on healthy eating and problem-solving skills, improving communication, and using community resources	PwT2D with multi-ethnic backgrounds in five primary care clinics of managed care organisation in Colorado, USA (n = 463)	<ul style="list-style-type: none"> <li>• Linguistic and cultural programme adaptation</li> <li>• Virtual programme combined with in-person follow-up</li> <li>• Information about local resources</li> <li>• Service redesign (IT integration)</li> </ul>
Goderis <i>et al.</i> (2010), Belgium	Randomised controlled trial	Evaluate quality improvement programme to support general practice in chronic care delivery	GP, diabetologist, diabetes specialist nurse, dietitian, health psychologist; based on chronic care model and transtheoretical model of change	GP: treatment protocol supported by two postgraduate training sessions, case coaching, annual benchmarking, referral to interdisciplinary team for diabetes education and incentives (€60/patient)  Additional training: three monthly follow-ups, stimulated shared care with an interdisciplinary team, two sessions on person-centred communication,	PwT2D in 74 primary care practices in Belgium (n = 2256)	<ul style="list-style-type: none"> <li>• Treatment protocol and shared-care guidelines</li> <li>• Training of HCPs (case coaching)</li> <li>• Learning strategy (person-centred communication)</li> <li>• Reorganisation of local care team</li> </ul>

Author, year, country	Study design	Purpose/aim	Main professionals and theoretical framework	Intervention	Participants and location	Key concepts/themes
				motivational interviewing to facilitate behaviour change and peer discussion Patient: free patient education in primary care location or in patient's home by interdisciplinary team; material for measuring blood glucose		<ul style="list-style-type: none"> <li>• Feedback on performance</li> <li>• Financial incentives</li> </ul>
Katon <i>et al.</i> (2010), USA	Randomised controlled trial	Evaluate coordinated care management of poorly controlled PwT2D with multiple coexisting conditions	GP, primary care nurse, specialists (psychologist, psychiatrist); based on problem-solving strategies	Guideline-based treat-to-target disease management of multiple coexisting conditions with primary care nurse to support self-care; proactive structured follow-up in primary care every 2 to 3 weeks; educational self-care material Weekly case review and supervision of primary care nurse with a psychiatrist, psychologist and GP; tailored treatment with medication Maintenance plan that includes stress reduction, behavioural goals, use of medications and early symptoms of worsening conditions; monthly follow-up phone calls	PwT2D with multiple conditions (diabetes and/or coronary heart disease and depression) from 14 primary care clinics in an integrated healthcare system in Washington State, USA (n = 214)	<ul style="list-style-type: none"> <li>• Coordination of multiple care needs</li> <li>• Treatment protocol</li> <li>• Collaboration of GP, primary care nurse and specialists</li> <li>• Learning strategy (person-centred communication)</li> <li>• Regular follow-up</li> </ul>
Ko <i>et al.</i> (2007), South Korea	Randomised controlled trial	Evaluate the effectiveness of intensive structured group education with regular follow-up	Diabetologist, diabetes specialist nurse, dietician, ophthalmologist, pharmacist, psychologist, GP and medical rehabilitation specialists; based on cognitive behavioural theory	Five 6-hour diabetes group education sessions during hospital stay addressing disease understanding, treatment skills and behavioural strategies to encourage self-management activities; invitation of family members to attend Regular 3-month follow-up in outpatient clinic by diabetes specialist nurse and physician; reminder on non-attendance Annual 3-hour group session to review self-management	PwT2D recruited in university-affiliated diabetes centre in South Korea (n = 547)	<ul style="list-style-type: none"> <li>• Collaboration of multidisciplinary diabetes care team</li> <li>• Social support (family, other carer)</li> <li>• Adaptation to local needs</li> <li>• Regular follow-up</li> <li>• Recall system</li> </ul>

Author, year, country	Study design	Purpose/aim	Main professionals and theoretical framework	Intervention	Participants and location	Key concepts/themes
Piatt <i>et al.</i> (2006), USA	Randomised controlled trial	Evaluate the effect of a multifactorial intervention using the chronic care model	GP, nurse practitioner, physician assistant, psychologist, certified diabetes educator (CDE: nurse, dietician); based on empowerment	PwT2D: Six weekly sessions of structured curriculum-based diabetes self-management training facilitated by CDE, followed by monthly support groups up to 12 months GP: One problem-based learning session, case coaching; CDE for consultation in primary care on "diabetes day" Chart reviews against national standard	PwT2D from 11 primary care practices in an underserved suburb of Pittsburgh, Pennsylvania, USA (n = 119)	<ul style="list-style-type: none"> <li>• Training of HCPs (problem-based learning, case coaching)</li> <li>• Adaptation to local needs</li> <li>• System redesign</li> <li>• Treatment protocol</li> <li>• Feedback on performance</li> </ul>
Russell <i>et al.</i> (2013), Australia	Non-randomised controlled trial	Evaluate an integrated primary/specialist community care model for complex T2D management	Diabetologist, GP with advanced skills in diabetes care, diabetes specialist nurse, dietician, psychologist, podiatrist; based on empowerment	Weekly multidisciplinary clinic with co-consultation of diabetologists and GP with advanced skills and PwT2D in primary care Postgraduate online training of GP in advanced diabetes care, with case coaching of GP and primary care nurse Biweekly telephone contact to intensify insulin treatment, follow-up phone calls at 6-week and 3-month intervals by diabetes specialist nurse	PwT2D from a tertiary hospital in lower socio-economic suburb of South Brisbane, Australia (n = 330)	<ul style="list-style-type: none"> <li>• Training of HCPs (postgraduate online training, case coaching)</li> <li>• Relationship of HCPs and patients in multidisciplinary care</li> <li>• Local access to diabetes care (co-consultation)</li> <li>• System redesign</li> <li>• Regular follow-up</li> </ul>
Rygg <i>et al.</i> (2012), Norway	Randomised controlled trial	Evaluate a locally developed ongoing group-based diabetes self-management education programme for PwT2D	Diabetes specialist nurse, physician, physiotherapist, dietician, PwT2D; based on health education using problem-solving strategies and brief solution-focused therapy	Three 5-hour weekly sessions in outpatient clinics led by diabetes specialist nurses with input from multiple HCPs and experienced PwT2D; extended break time for social interactions Introductory lecture followed by interactive learning and skills training on disease, physical activity, glycaemic control and problem-solving; group discussion of patient experience	PwT2D from two hospital settings within the same hospital trust in Central Norway (n = 146)	<ul style="list-style-type: none"> <li>• Locally developed programme</li> <li>• Patient referral from GPs</li> <li>• Collaboration of diabetes team and PwT2D</li> </ul>

Author, year, country	Study design	Purpose/aim	Main professionals and theoretical framework	Intervention	Participants and location	Key concepts/themes
Sarkadi & Rosenqvist (2004), Sweden	Randomised controlled trial	Evaluate the effectiveness of an experience-based group educational programme	Pharmacist, diabetes specialist nurse; based on experience-based learning	<p>PwT2D: monthly group meetings to discuss group questions based on experience and individual experiments; sharing diaries and reflecting on practical aspects (preparing food, self-monitoring, walking, choice, emotional aspects) within the group</p> <p>HCP training (3 days): same experience-based learning using identical educational materials (video, booklet, game) as used in the programme for PwT2D</p> <p>Continuous HCP training with regular follow-up meetings every 6 months</p>	PwT2D from participating pharmacies in Sweden (n = 77)	<ul style="list-style-type: none"> <li>• Learning strategy (sharing of views, beliefs and attitudes)</li> <li>• Training of HCPs (reflection on experience-based learning)</li> <li>• Local access to diabetes care</li> </ul>
Trento <i>et al.</i> (2010), Italy	Randomised controlled trial	Evaluate the transferability of group self-management education	Physician, nurse, dietitian, educator in the role as facilitator; based on principles of adult education	<p>Seven 1-hour group sessions every 3–4 months on diabetes-related topics; programme may be repeated for reinforcement after 2 years</p> <p>PwT2D training with group work, hands-on activities, problem-solving, real-life simulations and role playing in same group to support group cohesion and interpersonal relationships</p> <p>HCP training in using theoretical framework, teaching manual and materials</p>	PwT2D from 13 hospital-based diabetes outpatient clinics in Italy (n = 815)	<ul style="list-style-type: none"> <li>• Training of HCPs (understanding theoretical framework, pedagogical principles)</li> <li>• Peer support (identifying with group, disease and activity)</li> <li>• Group care in local service delivery</li> <li>• Service redesign</li> <li>• Regular follow-up</li> </ul>

*Note:* GP: general practitioner; HCPs: healthcare professionals; PwT2D: people with type 2 diabetes

**Table 2-3** Summary of qualitative studies included in the review

Author, year, country	Study design	Purpose/aim	Type of data collection	Themes in articles	Participants	Key concepts/themes
Adolfsson <i>et al.</i> (2008), Sweden	Qualitative content analysis	Explore patients' experiences of participating in an empowerment group education programme or receiving individual counselling	Semi-structured individual interviews	<p>Relationships:</p> <ul style="list-style-type: none"> <li>• Unequal participation in interactions using an instructive approach</li> <li>• Equal contribution in interactions using an empowerment strategy</li> </ul> <p>Learning:</p> <ul style="list-style-type: none"> <li>• Following advice and recommendations in instructions</li> <li>• Participating in learning process in empowerment</li> </ul> <p>Controlling the disease:</p> <ul style="list-style-type: none"> <li>• Externally controlled by professional expertise observed in instructions</li> <li>• Internally controlled by understanding how to actively participate in self-management observed in empowerment</li> </ul>	PwT2D previously participating in RCT (Adolfsson <i>et al.</i> 2007) (n = 28)	<ul style="list-style-type: none"> <li>• Positions of HCPs and patients in interactions</li> <li>• Learning style in programme delivery</li> <li>• Understanding of self-management</li> </ul>
Balcou-Debussche and Debussche (2009), France	Qualitative content analysis using constant comparative approach; ethnographic observation	Assess the effects of self-management education on the individual practices of patients	<ul style="list-style-type: none"> <li>• Semi-structured individual interviews</li> <li>• Ethnographic observations of interactions in hospital and at participants' homes</li> </ul>	<p>The hospital system:</p> <ul style="list-style-type: none"> <li>• In the hospital, HCPs recommend treatments for PwT2D to follow</li> <li>• Subordinate role of PwT2D to medical power</li> </ul> <p>The suspension of reality in hospital:</p> <ul style="list-style-type: none"> <li>• HCPs manage disease and PwT2D cooperate: "I was very well, as though the diabetes had disappeared"</li> </ul> <p>From hospital to home:</p> <ul style="list-style-type: none"> <li>• Implementation of learning into social, economic and family environment: "If you don't eat any cake, they ask if there is something wrong with it"</li> </ul>	PwT2D participated in same delivery location as in RCT (Debussche <i>et al.</i> 2012) (n = 42)	<ul style="list-style-type: none"> <li>• Delivery location of self-management education</li> <li>• Responsibility for disease management</li> <li>• Transfer of learning into routine</li> </ul>

Author, year, country	Study design	Purpose/aim	Type of data collection	Themes in articles	Participants	Key concepts/themes
Glasgow <i>et al.</i> (2012a), USA	Mixed methods using thematic content analyses	Evaluate the extent to which a web-based self-management programme was integrated into patients' primary care	<ul style="list-style-type: none"> <li>• Patient satisfaction survey with four open-ended questions</li> <li>• Qualitative interviews with physicians</li> <li>• Chart reviews of participants</li> <li>• Documentation of process implementation</li> </ul>	Themes in GP interviews: <ul style="list-style-type: none"> <li>• Reinforce behavioural goals</li> <li>• Easy access to information</li> <li>• Integrate with existing programmes</li> <li>• Concerns related to computer access and literacy</li> </ul>	<ul style="list-style-type: none"> <li>• PwT2D participating in intervention groups in PCT (Glasgow <i>et al.</i> 2012b) (n = 331)</li> <li>• GPs in five primary care clinics of integrated managed care organisation in Colorado, USA (n = 11)</li> </ul>	<ul style="list-style-type: none"> <li>• Reinforcement strategy through in-person follow-up</li> <li>• Service redesign (IT integration)</li> <li>• Acceptance and/or compatibility of IT resource</li> </ul>
Goderis <i>et al.</i> (2009), Belgium	Thematic analysis with theory-based deductive coding using an implementation model	Evaluate barriers and facilitators to high-quality diabetes care as experienced by primary care physicians	Semi-structured individual interviews	Barriers to high-quality diabetes care: <ul style="list-style-type: none"> <li>• Lack of knowledge and awareness of GPs practice performance</li> <li>• Scepticism about evidence-based treatment and shared-care collaboration</li> </ul> Factors facilitating change: <ul style="list-style-type: none"> <li>• Treatment protocol, postgraduate education, case coaching, benchmarking feedback</li> <li>• Increased contact and communication with colleagues from other disciplines</li> <li>• Role redesign, reassigning responsibility</li> </ul>	GPs participating in RCT (Goderis <i>et al.</i> 2010) (n = 20)	<ul style="list-style-type: none"> <li>• Training of HCPs (interdisciplinary teamwork)</li> <li>• Treatment protocol and shared-care guidelines</li> <li>• Adaptation to local needs</li> <li>• Service redesign</li> </ul>



Author, year, country	Study design	Purpose/aim	Type of data collection	Themes in articles	Participants	Key concepts/themes
Hepworth <i>et al.</i> (2013), Australia	Thematic analysis	Explore a new model of integrated primary/secondary care for type 2 diabetes management	Semi-structured individual interviews	Person-centred care: <ul style="list-style-type: none"> <li>• Accessibility in community</li> <li>• Delivery within a positive healthcare environment</li> </ul> Effective multi-professional teamwork: <ul style="list-style-type: none"> <li>• Clear communication</li> </ul> Empowering patient: <ul style="list-style-type: none"> <li>• Relationship (HCPs and patients)</li> <li>• Patients seeing themselves as part of team-based care</li> </ul>	PwT2D previously participating in non-randomised controlled trial (Russell <i>et al.</i> 2013) (n = 10)	<ul style="list-style-type: none"> <li>• Local access to diabetes care</li> <li>• Collaboration with multidisciplinary diabetes care team</li> <li>• Relationship of HCPs and patients in multidisciplinary care</li> <li>• Regular follow-up</li> </ul>
Mandalia <i>et al.</i> (2014), UK	Thematic analysis using comparative and framework approaches	Elicit the views of key stakeholders (patients and educator) about using lay people and professional educators with equal roles to deliver diabetes education	Telephone interviews	<ul style="list-style-type: none"> <li>• Differences in knowledge of HCP and lay educator</li> <li>• Peer status in relation to disease experience</li> <li>• Feasibility of using lay educators in self-management education</li> </ul>	PwT2D as well as lay and HCP educators previously participating in non-randomised controlled trial (Carey <i>et al.</i> 2014) (n = 27)	<ul style="list-style-type: none"> <li>• Complementary role functions of HCPs and peer educators</li> <li>• Peer support (identification with common experience)</li> </ul>
Rygg <i>et al.</i> (2010) Norway	Systematic text condensation (thematic cross-case analysis)	Explore reasons for participating in group-based diabetes self-management education for patients with type 2 diabetes	Semi-structured focus groups and individual interviews	Experiencing practical problems: <ul style="list-style-type: none"> <li>• Insufficient answers from HCPs</li> <li>• Contradictory information from different sources</li> </ul> Feeling insecure: <ul style="list-style-type: none"> <li>• Lacking communication with other PwT2D</li> <li>• Missing confirmation about treatment implementation</li> </ul>	PwT2D from self-management education groups, some previously participating in RCT (Rygg <i>et al.</i> 2012) (n = 22)	<ul style="list-style-type: none"> <li>• Local access to peer group</li> <li>• Peer support (practical support regarding problem-solving strategies)</li> <li>• Social support (experiencing confirmation within a group)</li> </ul>

Note: GP: general practitioner; HCP: healthcare professional; PwT2D: people with type 2 diabetes; PCT: pragmatic clinical trial; RCT: randomised controlled trial

## **2.5 Synthesis of findings**

This section presents the synthesis of the themes and concepts identified in the studies and explains how they contribute to the conceptualisation of integration in relation to self-management education, as related to the CAS components (non-linear processes, emergent behaviour, co-evolution using simple rules and self-organisation). The themes and concepts were clustered around the perceptions of integration (Kodner & Spreeuwenberg 2002) based on care delivery, clinical aspects, organisational collaboration, and access to resources and community structures.

This synthesis characterises the dynamics of the non-linear processes in care delivery which are expressed as interpersonal relationships and in the clinical interactions formed by the programme ethos. Furthermore, it identifies the behaviours that developed shared learning and recognises the adaptive processes which reflect the context and the organisational structures that advance integration. An example of the coding and analysis processes is given in Appendix VII.

The synthesis interprets the five identified constructs which explain the components of integration as: 1) constructed through interpersonal relationships, 2) shaped by the underpinning ethos of a programme, 3) created through shared learning, 4) developed through adapting to context and 5) mediated by the organisation of the care system. The components of integration are detailed in the following sections.

### **2.5.1 Overview of findings**

The identified concepts in the individual studies were extracted and tabulated to construct a matrix representing the theoretical framework that, in a CIS, is expressed as a synthesising argument (Table 2-4). The matrix populates the components of integration with the main concepts identified from the source studies.

**Table 2-4** Components of integration in relation to self-management education

Source	Interpersonal relationship	Programme ethos	Shared learning	Adapting to context	Care system organisation
Adolfsson <i>et al.</i> (2007)	Reflective peer discussion	Empowerment model	HCPs' understanding of theoretical concepts and delivery mode		
Adolfsson <i>et al.</i> (2008)	Positions of HCPs and patients in interactions	Empowerment model	Understanding of self-management	Learning style in programme delivery	
Balcou-Debussche & Debusche (2009)	Responsibility for disease management	Problem-solving strategies	Transfer of learning into routine	Delivery location of self-management education	
Carey <i>et al.</i> (2014)	Equal roles of HCPs and peer educators in interactions	Combined theoretical frameworks	Joint training of HCPs and laypeople in programme delivery		
Deakin <i>et al.</i> (2006)	Interactions with peers	Empowerment model (problem-solving strategies)	Peer support by trained layperson	Local access (community); linguistic and cultural programme adaptation	
Debussche <i>et al.</i> (2012)		Problem-solving strategies	Collaboration of multidisciplinary diabetes care team	Linguistic and cultural programme adaptation	Regular follow-up (by multidisciplinary team); recall system
Glasgow <i>et al.</i> (2012a)		Combined theoretical frameworks	Reinforcement strategy through in person follow-up	Acceptance and/or compatibility of IT resource	Service redesign (IT integration)
Glasgow <i>et al.</i> (2012b)		Combined theoretical frameworks	Virtual programme combined with in-person follow-up	Linguistic and cultural programme adaptation; information local resources	Service redesign (IT integration)
Goderis <i>et al.</i> (2009)		Combined theoretical frameworks	Training of HCPs in interdisciplinary teamwork	Adaptation to local needs	Service redesign; treatment protocol and shared-care guidelines
Goderis <i>et al.</i> (2010)	Learning strategy (person-centred communication)	Combined theoretical frameworks	Training of HCPs through case coaching	Reorganisation of local care team; feedback on performance	Treatment protocol and shared-care guidelines; financial incentives

Source	Interpersonal relationship	Programme ethos	Shared learning	Adapting to context	Care system organisation
Hepworth <i>et al.</i> (2013)	Relationship of HCPs and patients in multidisciplinary care	Empowerment	Collaboration with multidisciplinary diabetes care team	Local access to diabetes care	Regular follow-up
Katon <i>et al.</i> (2010)	Learning strategy (person-centred communication)	Problem-solving strategies	Collaboration of GP, primary care nurse and specialists	Coordination of multiple care needs	Treatment protocol; regular follow-up
Ko <i>et al.</i> (2007)	Social support (family, other carer)	Cognitive behavioural theory	Collaboration of multidisciplinary diabetes care team	Adaptation to local needs	Regular follow-up; recall system
Mandalia <i>et al.</i> (2014)	Peer support (identification with common experience)	Combined theoretical frameworks	Complementary role functions of HCPs and peer educators		
Piatt <i>et al.</i> (2006)		Empowerment	Training of HCPs (problem-based learning, case coaching)	Adaptation to local needs	System redesign; treatment protocol; feedback on performance
Russell <i>et al.</i> (2013)	Relationship of HCPs and patients in multidisciplinary care	Empowerment	Training of HCPs (postgraduate online training, case coaching)	Local access to diabetes care (co-consultation)	Regular follow-up; system redesign
Rygg <i>et al.</i> (2010)	Social support (experiencing confirmation within a group)	Combined theoretical frameworks	Peer support (practical support regarding problem-solving strategies)	Local access to peer group	
Rygg <i>et al.</i> (2012)		Combined theoretical frameworks	Collaboration of diabetes care team and PwT2D	Locally developed programme; patient referral from GPs	
Sarkadi & Rosenqvist (2004)	Learning strategy (sharing of views, beliefs and attitudes)	Experience-based learning	Training of HCPs (reflection on experience-based learning)	Local access to diabetes care	
Trento <i>et al.</i> (2010)	Peer support (identifying with group, disease and activity)	Principles of adult learning	Training of HCPs (theoretical framework and pedagogical principles)	Group care in local service delivery	System redesign; recall follow-up

*Note:* GP: general practitioner; HCPs: healthcare professionals; PwT2D: people with type 2 diabetes; IT: information technology

In the following sections, each of the five components of integration is presented to provide more details on how the theoretical framework is linked to the key concepts identified in the quantitative and qualitative source studies. Each component is illustrated with first-order excerpts from the qualitative sources.

### **2.5.2 Integration is constructed through interpersonal relationships**

Integrating interpersonal relationships into self-management education relates to the concepts that identify the different roles and positions that HCPs and patients have during their interactions. A key feature identified in multiple studies was the manner in which the HCPs developed relationships with patients, which was found to mediate the degree to which patients engaged in self-management behaviours (Sarkadi & Rosenqvist 2004, Deakin *et al.* 2006, Adolfsson *et al.* 2007, Adolfsson *et al.* 2008, Balcou-Debussche & Debussche 2009, Rygg *et al.* 2010, Trento *et al.* 2010, Hepworth *et al.* 2013, Russell *et al.* 2013, Carey *et al.* 2014, Mandalia *et al.* 2014). As observed in Deakin *et al.* (2006), Trento *et al.* (2010) and Carey *et al.* (2014) such engagement was associated with a more person-centred approach, in which the HCPs acted as partners rather than as experts giving prescriptive advice. In these examples, the HCPs interacted as equals with the patients to encourage the patients' active participation. This approach was particularly evident in the context of group education programmes in which participants shared experiences as equals (Deakin *et al.* 2006, Rygg *et al.* 2010, Trento *et al.* 2010, Carey *et al.* 2014, Mandalia *et al.* 2014).

Another important mediating factor in the delivery of a person-centred approach was whether the HCPs had been given training in such an approach, with studies showing that training had some impact on the level of their interactions experienced by patients (Sarkadi & Rosenqvist 2004, Adolfsson *et al.* 2007, Adolfsson *et al.* 2008, Goderis *et al.* 2010, Katon *et al.* 2010, Hepworth *et al.* 2013, Russell *et al.* 2013). This is illustrated in

the following example of a patient account from a care setting where the HCPs had been trained in person-centred care delivery:

The high regard that participants had for the service was specifically linked to how the staff at the clinic related to patients; ... certainly they're very supportive in what they do and they treat you as a person, not as a number, so all those are a definite plus. (Hepworth *et al.* 2013, p.209)

It is likely that the impact of the HCPs' training implied in the example above may have been mediated by the care system within the context of the study, resulting in multidisciplinary care delivery being encouraged, as suggested in the following example:

I have stuck to all the rules that they have given me and that would never have happened if the whole system wasn't in place ... working with the whole team I've been able to turn my liver and kidney functions back around. (Hepworth *et al.* 2013, p.211)

These accounts were expressed in the context of the study of Russell *et al.* (2013), which evaluated an intervention led by general practitioners to encourage patients to participate in their self-management care. The study showed that the participants in the intervention group were three times more likely to achieve their therapy goals within a 12-month period compared to the control group; however, the intervention group's level of healthcare service use was also three times higher. Considering the patient experiences presented by Hepworth *et al.* (2013), the study implies that the patients followed the individual instructions received from HCPs, which they seemed to have appreciated in context, while it remains less clear to what extent the patients were encouraged to actively participate in self-management education. As Russell *et al.* (2013) indicated, participation in self-management education was low and patients' self-efficacy, as measured by the locally adapted and validated diabetes self-efficacy scale (Rapley *et al.* 2003), did not improve in either the intervention or control group. This may indicate that the HCPs in the study primarily instructed participants regarding the handling techniques required for disease treatment.

A similar situation was described in the study by Balcou-Debussche and Debussche (2009), which used observational data collected in group education sessions with patients conducted in a hospital setting, indicating that the HCPs in the group sessions were more vocal than patients, tending to give information rather than listening to and interacting with patients:

Field note: The time for exchanges between the healthcare professional and the patients breaks down as follows: about 80% for the carer, 20% for the 5 patients present. The patients' interventions are closely linked to the questions and prompting from the trainer: The patients acquiesce and go in the direction desired by the trainer. At the end of the session the trainer is persuaded that "the messages considered important have been successfully conveyed". (Balcou-Debussche & Debussche 2009, p.1105)

The examples above suggest that the extent to which HCPs put a person-centred approach into action may relate to their outlook and understanding of patient participation in self-management and thus influence their roles and positioning in their interactions with patients. Some of the studied programmes involved the use of a peer educator. The peer educators seemed to have a mediating effect on the positions of patients and HCPs in the delivery of the self-management education, helping HCPs to better integrate the personal lived experience of the patients within the programmes and making the dynamic between the HCPs and the patients more equal (Deakin *et al.* 2006, Trento *et al.* 2010, Carey *et al.* 2014, Mandalia *et al.* 2014). The study of Mandalia *et al.* (2014), for example, suggested that patients expected different insights from HCPs and peer educators because patients seemed to personally identify more with peer educators; they felt laypeople understood and shared their personal experiences and expected more medical information from the HCPs:

She [the peer educator] did know what she was talking about and she did know the pitfalls and what people would be facing, whereas the professional, you know the nurse, dealt with it from a professional point of view all the time but not from personally involved. (Mandalia *et al.* 2014, p.640)

In addition, the study of Carey *et al.* (2014), which evaluated participants' acceptance of adding a peer educator to the self-management education programme, reported comparable outcomes in both groups – whether they were exclusively delivered by HCPs or jointly delivered by peer educators and HCPs. While Carey *et al.* (2014) found no difference between the two groups, it may be that the exchange among peers might have enhanced the patients' likelihood of persevering in the intervention, thus allowing patients to feel more involved in the process of that delivery of programme, as suggested in the study by Deakin *et al.* (2006). The variations observed in HCPs' delivery of a person-centred approach to self-management education may reflect the training they received in supporting this approach (Sarkadi & Rosenqvist 2004, Adolfsson *et al.* 2007, Adolfsson *et al.* 2008, Goderis *et al.* 2010, Katon *et al.* 2010). The collected studies showed differences in learning approaches used to train HCPs. For example, in the studies of Sarkadi and Rosenqvist (2004) and Adolfsson *et al.* (2007), reflective strategies were used to encourage HCPs to think about patient disease experiences through simulations and discussions of an experience-based, participative learning approach. Furthermore, as Adolfsson *et al.* (2008) suggested, participative group learning may empower patients to actively participate in their own self-care, while an instructive knowledge transfer may actually hinder their involvement, as a result of the different dynamics that emerge from hierarchical and participative relationships.

Although not explicitly stated, there was some evidence from these studies that experience-based learning raised the awareness of some HCPs regarding their own training needs. For example, observational data obtained from videotaped training sessions in the study of Adolfsson *et al.* (2007) indicated that many HCPs insufficiently used listening skills and inadequately posed open questions to encourage patients' own problem-solving processes. This awareness-raising element in the training of HCPs elicited concern about the implementation of self-management support, which is advocated in many programme theories, such as the empowerment-based group



education approach (Anderson *et al.* 1991). While Adolfsson *et al.* (2007) found an improved level of patients' confidence in understanding their disease compared to the control group after 12 months (which may be related to the additional training of HCPs in person-centred care delivery), they did not conduct a follow-up investigation to determine whether the positive outcome was maintained over a longer period of time. However, as Trento *et al.* (2010) showed in their four-year follow-up study, favourable clinical and psychological outcomes may be maintained when using continuous peer support in group education facilitated by trained HCPs who encourage patients to actively participate in their self-management.

In summary, interpersonal relationship has been conceptualised as the interactions between patients and HCPs or peers that influence roles and positions in the learning experience of self-management education and is crucial for effectively integrating self-management education into routine care. These relationships may be shaped by whether HCPs have been trained in person-centred care delivery, which may help them support individual patients.

### **2.5.3 Integration is shaped by the underpinning ethos of a programme**

It was evident from the collective studies, an important factor in shaping how integration was operationalised within self-management education related to the underpinning psycho-educational theory and educational ethos of a programme. In several studies, the programmes emphasised adopting an empowerment-based model with problem-solving strategies (Deakin *et al.* 2006, Piatt *et al.* 2006, Adolfsson *et al.* 2007, Adolfsson *et al.* 2008, Balcou-Debussche & Debussche 2009, Debussche *et al.* 2012, Hepworth *et al.* 2013, Russell *et al.* 2013). Some other commonly used theoretical approaches combined social-cognitive theory with an emphasis on self-regulation and self-determination (Glasgow *et al.* 2012b, Carey *et al.* 2014). Other studies combined adult-based learning techniques, such as experience-based learning and problem-solving

approaches, with psychological tools, such as motivational interviewing or cognitive behavioural therapy techniques and the transtheoretical model of change (Sarkadi & Rosenqvist 2004, Ko *et al.* 2007, Goderis *et al.* 2010, Katon *et al.* 2010, Trento *et al.* 2010, Rygg *et al.* 2012). Overall, the studies described programmes that focused on the patient perspective within the learning context to promote patients' active participation in the learning experience.

A key focus in several studies was developing patients' self-efficacy (Sarkadi & Rosenqvist 2004, Deakin *et al.* 2006, Piatt *et al.* 2006, Adolfsson *et al.* 2007, Adolfsson *et al.* 2008, Trento *et al.* 2010, Debussche *et al.* 2012, Rygg *et al.* 2012, Carey *et al.* 2014, Mandalia *et al.* 2014). This was addressed by empowering participants to consider their current behaviours, to identify their priorities and the choices they can make and to develop strategies to enhance their exchanges with HCPs. These approaches were used both in individual consultations and in group education. In the context of group education, for example, Adolfsson *et al.* (2008) emphasised that participants may compare the experiences of others to their personal situations, which may encourage their engagement:

You walk around with questions you haven't got answers to, or that perhaps are way in the back of your head. Then it can be that others in this group ask just this question, and I get an answer to something I actually wasn't fully conscious of. (Adolfsson *et al.* 2008, p.991)

However, some of the studies indicated that these forms of person-centred education may not always transform the patients' ongoing care experiences and that the impact of the programme may not be sustained (Goderis *et al.* 2010, Debussche *et al.* 2012). Debussche *et al.* (2012) described a hospital-based training programme with regular patient follow-up that was disconnected from the normal daily experiences of patients:

Those people at the hospital, they really know what they are doing. You start to believe that everything is all right. Perhaps it goes a bit too far. ... You are in a setting that is controlled, measured, where they try to make it so that nothing bothers you, or almost nothing. They take over the responsibility for your life ... From the day you leave, you have to depend on yourself, and no matter what

people think, stress plays a big part in diabetes. You leave hospital and your worries get on top of you again. You get back to normal. (Balcou-Debussche & Debussche 2009, p.1109)

The example above illustrated that an educational programme's effect may not always filter through to patients' ongoing care and life experiences. Instead, participants' experience of an encouraging environment may only occur in the context of the programme sessions. Afterwards, they may become disengaged when their disease treatment is overshadowed by other life priorities or when the programme ethos of a course is not supported in their routine care. Rather than indicating the inadequacy of the approach, this may point to the failing of a specific programme that is not adequately integrated with patients' daily life experiences and ongoing care.

Some of the above studies used programmes that addressed the lack of integrating self-management behaviour into the patients' personal lives by including family, other carers or peers within the programme to strengthen the social support for the patients' self-management (Sarkadi & Rosenqvist 2004, Deakin *et al.* 2006, Piatt *et al.* 2006, Adolfsson *et al.* 2007, Ko *et al.* 2007, Rygg *et al.* 2010, Trento *et al.* 2010, Carey *et al.* 2014, Mandalia *et al.* 2014). As exemplified in Adolfsson *et al.* (2008), using and sharing the experiences of others with diabetes may assist patients in developing strategies and skills to sustain the self-management agenda they identified in the programme:

Being able to hear how they experience their disease, the tricks and solutions they have for food and exercise, is so important. The value of being many, being able to discuss, is that you get tips and ideas of how they solve various difficulties and that has great value. You learn a rather great deal. (Adolfsson *et al.* 2008, p.991)

In summary, programme ethos plays an important role in mediating how patients experience the integration of self-management education into their daily lives. While many programmes focus on transmitting knowledge of disease and treatment, learning from peers may encourage patients to transfer this knowledge into their life contexts

because the understanding becomes relevant for them. However, the extent to which the relevance of patient support continues beyond the programme may relate to the mechanisms within self-management education that enable participants to connect the personal goals they developed in the programme with their daily lives and their ongoing care interactions with HCPs.

#### **2.5.4 Integration is created through shared learning**

Shared learning experiences was identified in several studies to promote collaborative interactions between multiple HCPs as a way to develop a common understanding of self-management across different care delivery settings (Ko *et al.* 2007, Katon *et al.* 2010, Debussche *et al.* 2012, Rygg *et al.* 2012, Hepworth *et al.* 2013). Self-management education was delivered in a wide variety of settings: including hospital in- and outpatient clinics (Ko *et al.* 2007, Balcou-Debussche & Debussche 2009, Rygg *et al.* 2010, Trento *et al.* 2010, Debussche *et al.* 2012, Rygg *et al.* 2012), primary care (Piatt *et al.* 2006, Adolfsson *et al.* 2007, Adolfsson *et al.* 2008, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Glasgow *et al.* 2012a, Glasgow *et al.* 2012b, Hepworth *et al.* 2013, Russell *et al.* 2013, Carey *et al.* 2014, Mandalia *et al.* 2014), pharmacies (Sarkadi & Rosenqvist 2004) and community venues (Deakin *et al.* 2006). It would seem that different environments create divergent social associations that may influence how patients experience a programme. As suggested by Balcou-Debussche and Debussche (2009), patients may perceive a hospital setting to symbolise illness and treatment, whereas they may associate a community setting with neighbourhood support.

In order to develop a common understanding between HCPs, some programmes included case coaching of primary care providers by diabetes specialists (Piatt *et al.* 2006, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Russell *et al.* 2013). These studies also underlined the importance of good communication between the different sectors of care, especially as primary care is increasingly accountable for

diabetes management. As Goderis *et al.* (2009) found, when HCPs knew each other's responsibilities, it facilitated collaboration and increased their acceptance of shared care:

To summarize this project: we started with a good protocol and established better channels of communication between primary and specialist care. ... The delineation of responsibilities and degree of familiarity among the partners were very important in making it easier to me to refer more patients. (Goderis *et al.* 2009, p.46)

Overall, programmes that invested time and effort in building trust and collaborative care resulted in increased acceptance by HCPs, as described in several studies (Sarkadi & Rosenqvist 2004, Piatt *et al.* 2006, Adolfsson *et al.* 2007, Ko *et al.* 2007, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Trento *et al.* 2010, Debussche *et al.* 2012, Rygg *et al.* 2012, Hepworth *et al.* 2013, Russell *et al.* 2013, Carey *et al.* 2014, Mandalia *et al.* 2014). These studies included mediating factors that sought to encourage collaboration and to harmonise the perspectives and default approaches of the different disciplines involved in patient care. Having a shared structure for care delivery and reflecting the programme ethos with a common and open approach to communication seem to be important in achieving team collaboration, which may in turn improve the integration of self-management support experienced by patients.

Only a few studies included wider multidisciplinary education as the format to share the theoretical programme approach between HCPs and to instil the care context with that approach (Sarkadi & Rosenqvist 2004, Adolfsson *et al.* 2007, Trento *et al.* 2010). These studies described multidisciplinary training that encouraged HCPs to consider their role in supporting self-management and building up care networks to ease integrating self-management education into clinical practice for patients' benefit. Furthermore, clear communication and professional training may advance the level of collaboration and coordination of the multiple care needs observed in patients with co-morbidities, as shown in several studies (Piatt *et al.* 2006, Goderis *et al.* 2010, Katon *et al.* 2010, Russell *et al.* 2013).

In summary, the concept of shared learning refers to the conditions that encourage teamwork, such as observed in multidisciplinary trainings of HCPs. This concept of learning may be expanded to include patients as they may associate their learning experience to the care environment. As a result, shared learning furthers collaboration and an integrated care experience, which may be facilitated through coordinated self-management education and delivery support.

### **2.5.5 Integration is developed through adapting to context**

Adapting self-management education to local and individual needs was identified to support HCPs and patients to better use these programmes (Sarkadi & Rosenqvist 2004, Deakin *et al.* 2006, Piatt *et al.* 2006, Ko *et al.* 2007, Balcou-Debussche & Debussche 2009, Goderis *et al.* 2009, Goderis *et al.* 2010, Rygg *et al.* 2010, Trento *et al.* 2010, Rygg *et al.* 2012, Hepworth *et al.* 2013, Russell *et al.* 2013). A few studies reported on self-management education programmes that were adapted to consider the linguistic and cultural needs of patients (Deakin *et al.* 2006, Debussche *et al.* 2012, Glasgow *et al.* 2012b). These studies used interpreters or bilingual HCPs to adapt the information to the participants' linguistic and socio-cultural background. In the study by Glasgow *et al.* (2012b), the programme materials were translated to address the issues of linguistic uncertainties that may have resulted from patients' participation in a programme in a non-native language. Furthermore, the participants in that study received additional advice on how to use their medical encounters and community diabetes resources.

Another study reported how participants adapted the programme content to reflect their cultural context. Balcou-Debussche and Debussche (2009) described how participants revalidated their cultural eating habits to match the recommended nutritional advice they were given:

What? I'm diabetic, and they are telling me to eat rice, beans, peas, and everything? Everybody thought we were going to eat French stuff and boiled stuff.

But no! The diet is typically Creole, there's no doubt about that. Some people were amazed.

Before, the doctor used to say, don't eat beans, don't eat rice, do eat meat, eat plenty of bread, and I don't know what else. But in there, they told us to eat rice. That's a good idea, a good thing to know. (Balcou-Debussche & Debussche 2009, p.1106)

A few studies developed programmes that enhanced access to self-management education in the community. These studies adapted programme delivery to local primary care needs by providing either specialist support for general practice (Goderis *et al.* 2010, Katon *et al.* 2010, Russell *et al.* 2013) or easy referral for self-management education (Rygg *et al.* 2012). Other studies integrated individual in-person follow-up appointments with a web-based interactive learning programme because this approach could flexibly adapt to the participants' time availability independent of their location (Glasgow *et al.* 2012a, Glasgow *et al.* 2012b). To adapt to participants' preferences, some programmes additionally offered self-management education by diabetes specialist nurses in home settings (Goderis *et al.* 2010), in primary care (Piatt *et al.* 2006, Katon *et al.* 2010, Russell *et al.* 2013) and in pharmacies (Sarkadi & Rosenqvist 2004) or group care with family support in local hospitals (Ko *et al.* 2007, Trento *et al.* 2010). The group setting helped participants to address their individual expectations within their life context as illustrated in the study of Rygg *et al.* (2010):

And then I thought; enlist so you can meet people in a similar situation ... . Chat with them and get some good advice, it could be helpful for me and my work, so I decided to enrol. (Rygg *et al.* 2010, p. 791)

Some studies reported on programmes that included an intensive follow-up; in Katon *et al.* (2010), for example, patients with co-morbidities were monitored every two to three weeks by experienced primary care nurses.

In summary, adapting to context shows variable programme approaches to characterise how programmes consider patients' and HCPs' needs to enhance their acceptance of

self-management education so that the programme may be integrated into the local care delivery system.

### **2.5.6 Integration is mediated by the organisation of the care system**

A key facet of integration expressed in several studies was the extent to which the programmes were embedded in the wider care system (Piatt *et al.* 2006, Ko *et al.* 2007, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Trento *et al.* 2010, Debussche *et al.* 2012, Glasgow *et al.* 2012a, Glasgow *et al.* 2012b, Hepworth *et al.* 2013, Russell *et al.* 2013). The level of embeddedness was related to both normative mechanisms, such as guidelines and care pathways, and contextual mediators representing the relationship between the programme and wider processes of patient care (Piatt *et al.* 2006, Ko *et al.* 2007, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Trento *et al.* 2010, Debussche *et al.* 2012, Hepworth *et al.* 2013, Russell *et al.* 2013). Such communication processes can be facilitated by using information technology (IT) to transfer information (Glasgow *et al.* 2012a, Glasgow *et al.* 2012b).

Several studies contained programmes that included treatment protocols and guidelines with regular follow-up and recall systems to integrate the programme into the care delivery process (Piatt *et al.* 2006, Ko *et al.* 2007, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Trento *et al.* 2010, Debussche *et al.* 2012, Hepworth *et al.* 2013, Russell *et al.* 2013). While many HCPs followed these protocols, in Goderis *et al.* (2009), for example, some conveyed that before the study they did not pay attention to or follow up on the patient's personal self-management goals and the behavioural aspect of diabetes care:

I didn't observe major behavioural changes in most patients, but this may be associated with my own passive attitude. I made no changes in my organization of care and I did not spend enough time at it. (Goderis *et al.* 2009, p. 45)



The level of collaboration and coordination between HCPs in different parts of the system was also important. As was evident in several studies, a redesign of the delivery system in primary and secondary care using shared-care guidelines was essential for collaborative and coordinated working (Piatt *et al.* 2006, Goderis *et al.* 2009, Goderis *et al.* 2010, Katon *et al.* 2010, Trento *et al.* 2010, Glasgow *et al.* 2012a, Glasgow *et al.* 2012b, Russell *et al.* 2013). In these studies, for example, the clear outline of the patient care pathway with treatment protocols eased the conduct and delivery of the multifaceted programmes in primary care and outpatient clinics.

Information technology was also used in some programmes as a tool for integrating self-management education into the care delivery process for patients (Glasgow *et al.* 2012a, Glasgow *et al.* 2012b). In these studies, patients in primary care settings shared information regarding their personal goals and used interactive health communication applications to virtually participate in self-management education. While these approaches were seen to have the potential to enable knowledge transfer between HCPs and patients, Glasgow *et al.* (2012a) also raised concerns that limited literacy and computer access may disadvantage some patients:

I agree that using more modern technology with applications and smart phones ... but many patients cannot afford their medications right now and will not be upgrading technology any time soon. (Glasgow *et al.* 2012a, p. 319)

The data suggested that integrating technology-based tools into routine practice required both acceptance of and access to the technology as well as the skills required for optimal use by both patients and HCPs.

In summary, integration of self-management education is mediated by a care system's organisation and strategies that make it possible to translate the programme into routine care. This kind of organisation is shaped by structures and processes defined in guidelines and protocols and by the use of communication technologies that facilitate the transfer of information, which may be important for ensuring that a programme is

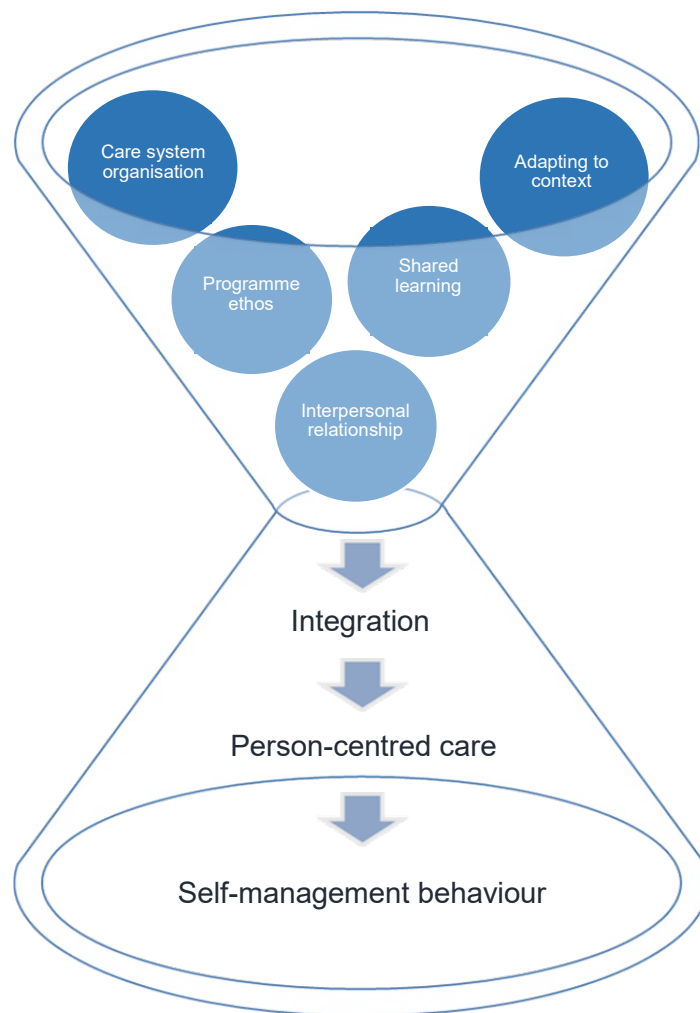
connected with ongoing patient care.

## **2.6 Interactions and relationships between components of integration**

This section introduces the conceptualisation that integrates the five components in order to understand their interactions and relationships. These interfaces may influence the HCPs' delivery of self-management education and the patients' self-management behaviour within the system in which the programme is delivered. The five components of integration were conceptualised in a cascade-like form of interaction, assuming a systemic non-linear interconnectedness (Figure 2-2).

The theoretical model suggests that the integration of the components may influence the delivery of person-centred care and self-management behaviour according to the importance and priority given to each individual component. One component in the model illustrates the interpersonal relationship that is expressed by interactions between the patients and HCPs during self-management education. This interactive process is likely driven by the underlying positions people take in their exchanges, which are observable in the ways they participate and contribute. Interpersonal integration refers to person-centred interactions that may interrelate with the other components – for example, by influencing how shared learning is encouraged in programme delivery. The delivery, in response, may affect the implementation of a programme's ethos that underpins self-management education in practice. The programme approach, in return, may guide and influence HCPs' positions in conducting self-management education. Some self-management education programmes adapt the content and delivery mode to the patient context. The model reflects this contextualisation to address the needs and preferences of a diverse population. The model considers the collaborative interactions that are observable in self-management education and that are delivered through multiple HCPs. Such collaborative interactions are reflected in the ways different healthcare services are connected. The system component in the model illustrates that structures and

processes, such as protocols, guidelines and IT systems, form the context for self-management education delivery and information transfer into routine care. In a whole-system approach, the different components of integration are expressed flexibly with dynamic interactions that may extend or diminish the sense of integration experienced by both patients and HCPs. Therefore, these interactions combined relate to the extent to which a person-centred care approach is delivered and self-management behaviour adopted.



**Figure 2-2** Theoretical model of how integration relates to self-management education

## 2.7 Discussion

This review identified the potential components of integration that may be manifest in self-management education programmes. Furthermore, it revealed the experiences and perspectives of people with T2DM and HCPs regarding integration in the context of such programmes in routine care. As a clear definition of integration in relation to self-management education has been missing in the literature, the findings of this study propose five multifaceted, interactive components that may characterise integration in this context. The components broadly cluster around the following: the interpersonal relationships observed in interactions between HCPs and patients, the programme ethos promoted in self-management education, the shared learning connected to care delivery, the adaptations necessary to deliver self-management education in context and the organisation of the care system in which these programmes are delivered. The findings also indicated deficits in the delivery of self-management education with regard to the patients, HCPs and care systems and how the programme ethos was used.

Interpersonal relationships may encourage patients to engage in self-management behaviour. These relationships are also influenced by how HCPs and patients perceive self-management and position themselves during their interactions. While it has been widely agreed that the relationship between HCPs and patients is essential in person-centred self-management education (Beach *et al.* 2006, McCormack *et al.* 2010, Entwistle & Watt 2013), some HCPs may be less aware of how different agendas and expectations shape their interactions with patients. Recognising these discrepancies is important because HCPs' views and behaviours may influence the delivery of self-management education; however, some programmes are still lacking the educational components that help HCPs understand how to effectively build relationships. This is complementary to the previous research of Hughes *et al.* (2017), which found that HCPs often focus on the biomedical aspect of chronic diseases and that this approach may reduce the degree to which they follow a person-centred approach of adapting self-

management education and support to an individual person's unique needs. This primarily biomedical focus further underlines the importance of HCPs engaging in training that improves their skills in person-centred care delivery. Moreover, many HCPs do not receive adequate training to support patients' self-management behaviour, as identified in a cross-country survey by Holt *et al.* (2013).

The diversity of participants in self-management education programmes creates dynamic interactions, which may require negotiations in order to arrive at an agreement for sharing experiences and perceptions, as the findings of this review imply. Such negotiations between patients and HCPs may also create uncertainties regarding participation in person-centred self-management education because both construct their interactions based on prior experience and understanding. Their interactions may either enhance or hinder patients' self-management behaviour because they may have different priorities. These findings emphasise that the behaviours of HCPs and patients emerge from their interpersonal relationships. In relation to a system perspective, the dynamic interactions between HCPs and patients may resemble the non-linear processes featured in a CAS (Ellis & Herbert 2011, Tsasis *et al.* 2012). Furthermore, the shared learning may relate to co-evolution, adapting to context may show similarities to self-organisation and interpersonal relationship may relate to emergent behaviour. Previous research has suggested that CAS theory offers an alternative to better understand the non-linear individual processes that may shape participation and exchange in person-centred care delivery (Innes & Booher 1999, Innes *et al.* 2005, Martin & Felix-Bortolotti 2014). Therefore, adapting self-management education to an individual context while also integrating the person-centred model of care delivery may support participants in adopting self-management behaviour.

Healthcare professionals also deliver self-management education using their prior knowledge, which may be based on a purely biomedical understanding of a given issue.

Hence, it is important to offer additional support to HCPs in the delivery of person-centred self-management education to address the issue of overly didactic approaches to self-management education (Snow *et al.* 2013, Bostrom *et al.* 2014a, Kennedy *et al.* 2014a, Hughes *et al.* 2017). This is an important challenge because a disconnect may exist between the model of person-centred self-management education and patients' follow-up experiences in their day-to-day care. This disparity may help explain why there is some inconclusive evidence regarding the impact of self-management education programmes on self-management behaviour and care outcomes, which may be furthered by the large variety of approaches used in diabetes self-management education programmes, often complex with multiple elements of delivery requiring a high skill level (Borgermans *et al.* 2008, Khunti *et al.* 2012).

Healthcare professionals and patients interact with each other most effectively when they are familiar with the language used in self-management education. For example, the manner in which HCPs give advice influences whether they facilitate an engaging environment or not. In addition, the language used by HCPs in sharing diabetes-related information may not be understood by people living with the condition – or may even lead to disengagement when the language used causes negative associations (Speight *et al.* 2012, Dickinson *et al.* 2017, Dunning *et al.* 2017). Ultimately, a person-centred approach involves listening to the words a patient uses so that HCPs can adapt their position and understand what really matters to the person living with diabetes. The potentially unfavourable effect of self-management education highlights the importance of reflecting on person-centred care delivery from different perspectives so that alternative viewpoints may be better espoused.

A key component of delivering an integrated approach to self-management education and support seems to be the extent to which an interdisciplinary team has a shared outlook and understanding of self-management. This relates to the interconnectedness (or lack thereof) of a team, which can be ensured through collaboration and information

exchanges. Coordination and collaboration are important in supporting access to care resources for providing self-management support that in turn may impact patient care outcomes (Peikes *et al.* 2009, Coulter *et al.* 2015). Again, these findings emphasise that the success of a self-management education programme may be predicated on the extent to which it is integrated into routine care.

Finally, the synthesis reveals that while some programmes have been developed in isolation from the wider context of care, others have considered the human, financial, social and training resources required to deliver effective programmes. While it is not clear to what extent such considerations impact the adoption and clinical effectiveness of a programme, developing system-level and community resources may be beneficial in order to maximise programme delivery (Curry *et al.* 2013, Greaves *et al.* 2013).

As suggested by the findings of the systematic literature review, integration in the context of self-management education may depend on dynamic interactions and relationships between HCPs and patients. Moreover, integration may be influenced by how HCPs apply the ethos of a programme, create shared learning occasions and adapt the programme to individual contexts. In addition, integration may be mediated by the organisation of a care system that supports the delivery of self-management education. Considering these components of integration is important for understanding the complexities associated with self-management education in the context of routine care to obtain sustainable outcomes of such programmes.

### *Presentation of the theoretical model*

This synthesis and model of integration were presented as a conceptual framework to diabetes specialist nurses (DSNs) at the annual conference of the Swiss Organisation of Diabetes Specialist Nurses in March 2016 in Bern. The participants were given a brief synopsis of the findings and model and then asked to consider whether anything was missing or should be omitted, the priorities for further developing the components and programme delivery and next steps for development. The model was discussed in a workshop that was simultaneously translated into French and German (the two major languages of Switzerland) in order to capture different linguistic interpretations and directly discuss any differences. It is interesting to note that some German-speaking DSNs prioritised the component of the programme ethos and suggested arranging the other components around the programme ethos, while French-speaking DSNs insisted on focusing on the component of interpersonal relationships. The model was also presented to interdisciplinary audiences at national and international conferences.

### *Limitations of synthesis*

As in many interpretive syntheses, although the studies did not all address the questions directly, the synthesis still extrapolated from those studies. Therefore, the synthesis relies on an interpretation of the studies. Nevertheless, as shown by the data, several patterns characterising the different components of integration were identified. While it is inherent to the methods used in a CIS, integrating qualitative and quantitative evidence from previous literature into a single review construes a theoretical framework based on an interpretation – and thus may partly remain vague (Dixon-Woods *et al.* 2005, Heyvaert *et al.* 2017). However, the proportion of quantitative and qualitative studies, the study designs, and their contribution to the conceptualisation were included in the review. To consider multiple perspectives in a CIS, a multidisciplinary review team could have been included, which was not possible in this context. However, the conceptualised model was



discussed in an interactive workshop with DSNs familiar with the topic and presented to interdisciplinary audiences at conferences. It was also discussed with supervisors, who provided some external scrutiny and additional expertise.

## **2.8 Conclusion**

This synthesis generated new perspectives on how integration in the context of self-management education programmes in routine care relates to patients, HCPs and system factors. The synthesis reveals some important features in which the level of integration may impact on the reach and power of person-centred models of self-management education. These features include the relationships between patients and HCPs as well as the care system and community context. While the observations largely concur with the conceptual model outlined in Chapter 1, they also introduce more detail, granularity and context in terms of how the interactions between the different components are expressed and how they might mediate programmes' impact. An insufficient integration of self-management education into routine care may impede the impact of these programmes and can be caused by a range of factors related to patients, HCPs and systems. These factors are further studied and developed in the empirical work that follows. Hence, examining these conceptualised components of integration in a real-world setting could refine the model of integrated self-management education.

## **Chapter 3 Research design and methodology**

This chapter outlines the research approach and rationale for adopting a case study methodology with a thematic narrative-based approach. It also details the case selection, data collection methods and procedures for data analysis and data interpretation. The chapter finishes with a critical reflection and analysis of the study methods.

### **3.1 Introduction**

The integration of person-centred self-management education into routine care is a multifaceted construct with interacting components that influence behaviour at different levels, as identified in the previous chapters. This study explored integration in the context of self-management education for people with T2DM in a natural setting.

#### **3.1.1 Study approach**

A qualitative research paradigm offered the most appropriate methodology for the study's purpose. To provide an in-depth understanding of integration within the context of self-management education, it was important to give voice to both the patients and HCPs to allow them to share their perspectives and experiences regarding such programmes in routine care. Direct observation of participants' interactions during the self-management education programme supplemented their interview accounts, and programme documents clarified the programme intentions.

In qualitative studies, the choice of methods is influenced by the study aim, and it is necessary to clarify the theoretical underpinnings of a chosen methodology (Denzin & Lincoln 2011, Polit & Beck 2012). The interpretive activities in a qualitative inquiry are based on the ontological and epistemological beliefs of the researchers; *ontology* explains how they perceive the social world and what can be known about it, while *epistemology* describes the nature and ways of acquiring that knowledge (Bryman 2012,

p.6). These assumptions about the nature of social phenomena influence how the research is conducted. In this study, it is assumed that reality and the social world are constructed from multiple perspectives and influenced by individual experiences, values and interactions between participants. The participants thus play an active role in the construction of social reality, to which they attach meaning, and the researcher is an integral part of the context being researched (Packer & Goicoechea 2010, Polit & Beck 2012, Creswell 2013).

In such circumstances, individuals seek understanding of the world they live and work in while interpreting interactions with others within a broader context, and they adapt their behaviour based on these interpretations (Denzin & Lincoln 2011). The researcher accepts the proposition that manifold perceptions of social reality exist and that qualitative research is fundamentally influenced by the relationship of the researcher to the people researched in the context in which they interact; therefore, a reflection of multiple realities that provides a situational understanding of the studied world at a specific moment (Riessman 2008, Creswell 2013, Silverman 2013).

Qualitative research may draw on different forms of reasoning to inform how the social world and phenomena can be construed (Riessman 2008, Polit & Beck 2012). For this study, both inductive and deductive reasoning were used, thus enabling theory-building by integrating prior theory with theory-generation processes.

To ensure that the most appropriate qualitative approach was adopted for the study, consideration was given to a number of different designs to assess how well each design addressed the research aims. These considerations are detailed below, and the potential merits of the different methodologies are outlined to provide a justification for the chosen approach of the study.

### *Grounded theory*

The grounded theory approach from a constructivist perspective as described by Charmaz (2006) was considered. Grounded theory is a good design for developing theory and for systematically explaining or understanding a process. It makes no *a priori* assumptions and aims to construct an understanding by translating observations and narratives into theories that explain the social context, interpersonal experiences and interactions within the field of inquiry (Charmaz 2006, Corbin & Strauss 2008). However, in this study, a theoretical framework has already been developed through the literature synthesis. As a result, a grounded theory approach would have enabled neither the consideration of the concept of integration nor the exploration of the model in a natural setting.

### *Phenomenology*

Consideration was also given to using a modified phenomenological approach, which can incorporate prior theory. Phenomenological research provides a deep understanding of a phenomenon by describing the lived experiences of individuals through the process of conscious meaning-making directed towards the object of interest (Moustakas 1994). In transcendental phenomenology, the focus is less on the researcher's interpretations and more on the description of the lived experiences of participants, separating the researcher's personal experience from the phenomenon being studied (Giorgi 2009). In phenomenological research, a small number of general questions are asked regarding what the participants experienced and how they perceived it (Moustakas 1994). These questions provide a rich description of the lived experiences and exclude interpretations of why they have experienced it. However, the aim of this study is to explore and develop an in-depth understanding of a phenomenon in a specific context and interpret why the phenomenon is experienced as it is in a bounded system. A phenomenological approach was thus not appropriate for addressing the research questions of this study.

## *Ethnography*

Another approach considered was critical ethnography based on a transformative or postmodern worldview (Thomas 1993). In critical ethnography, the meaning of a behaviour related to knowledge, society and political action is studied by addressing concerns pertaining to authority, power and control, inequality, empowerment, inequity, dominance, repression and victimisation (Thomas 1993). As a result, the researcher is immersed in the culture of the study participants, thus requiring a prolonged period of fieldwork in order to develop a complex and holistic cultural portrait of a group. This approach would have contributed to the interpretation of participants' shared meanings and provided an in-depth exploration of contextual factors, and it has some overlaps with a case study approach (Hammersley & Atkinson 2007). In both methodologies, data are collected from different sources, providing perspectives from multiple angles for data triangulation; however, this approach is relatively unstructured and open-ended, making reproducible reasoning for programme development more demanding (Roper & Shapira 2000). In an ethnographic approach, data collection develops during the conduct of the study (Hammersley & Atkinson 2007), whereas in case study research, data collection is designed beforehand and based on prior theory (Yin 2009).

While ethnography is concerned with the description of a group culture (Creswell 2013), it is limited because it is designed primarily for describing homogenous group settings. Conversely, this study involves an exploration of understandings across multiple heterogeneous groups. The central requirement for the study is to elicit an in-depth understanding of complex interactions within a system in order to further develop the theoretical framework of integration in the study context. Therefore, it was decided that this approach would not be best suited for addressing the study aim.

### *Thematic narrative-based case study research*

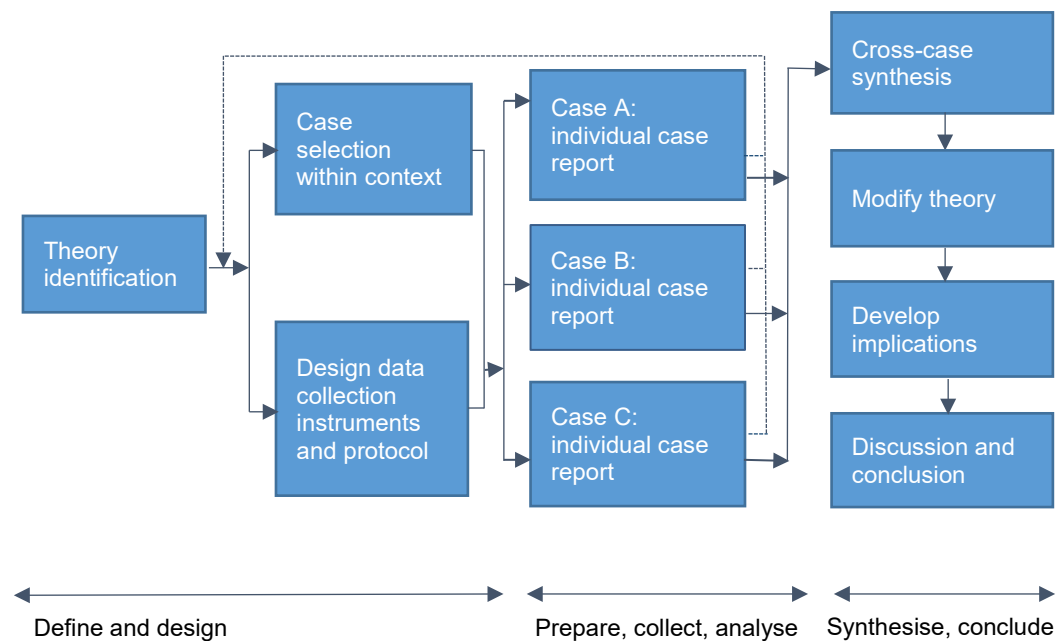
Case study research involves the study of a case within a real-life situation in order to explore an issue in its context. It is based on the philosophical assumption that the social world is constructed through multiple perspectives. A central aim of case study research is to understand an environment in the case context, which may be expressed through narratives (Yin 2009). Interpreting narratives is important for understanding the co-constructed reality in case-centred inquiry (Somers 1994, Riessman 2008). A narrative can refer the phenomenon studied in narrative research or the method used in the study to analyse spoken or written stories (Riessman 2008). Integrating the narrative and case study approaches unites the experience and context of a phenomenon in order to construct a view of social reality within a case study (Creswell 2013).

The perspectives offered by this combined approach of the case study methodology and narratives seemed best suited to the overall requirements of this study. The case study approach enables a detailed exploration of the complexities of integration in the context of self-management education because it allows for multiple methods for capturing data, thus helping to construct an understanding of that context. In particular, case study research offers the opportunity for an in-depth exploration of participants' experiences from different perspectives within the bounded system of the selected case (Yin 2009).

The thematic narrative approach enables the researcher to explore the ways in which participants co-create meaning through telling stories of their lived experiences (Riessman 2008). People use stories to understand their experiences of life transition by framing them in a narrative form, which may also indicate the way storytellers position themselves and reveal how storytellers are positioned by others (Lucius-Hoene & Deppermann 2000, Riessman 2008). Therefore, combining the case study methodology with a thematic narrative-based approach lends itself to exploring multiple perspectives of co-created meanings within a bounded system.

### 3.2 The case study design

Having explained the rationale for adopting a case study design with a thematic narrative-based approach to data analysis, this section details how these approaches guided the study. The overall study design follows the framework for case study research described by Yin (2009), which is presented schematically in Figure 3-1. Each element of Yin's framework is considered below in order to provide an overview of the study design and to explain how these elements relate to the research objectives.



**Figure 3-1** Case study approach, adapted from Yin (2009)

The theoretical proposition for the case study was derived from the theory of CAS and initially conceptualised to understand the key components of integration in relation to self-management education. Based on the theoretical representation, the context for conducting the case study was selected to explore the model of integrated self-management education in a natural setting. Within the bounded context, the perspectives and experiences of patients and HCPs who were participating in one of three different self-management educational programmes were explored. The data collection instruments were designed to address the research questions, and the study protocol

was defined for conducting the case study within the context. Different patterns and relationships were identified within each of the programmes and then integrated in the cross-case synthesis. In the synthesis, the theoretical proposition and possible rival explanations were pursued to confirm, challenge or extend the initial theoretical conceptualisation. Modification of the theoretical framework developed the basis of a logic model, which specifies the interactions and relationships within the model for replication and further programme design (Rogers 2008, Yin 2009). Logic models are graphic descriptions that identify important elements and interactions within a system (Hawe 2015). They help in outlining programme components and conceptualising interventions (Anderson *et al.* 2011, Rohwer *et al.* 2017). Therefore, the logic model contributes to the understanding of the interactions and relationships within self-management education programmes.

Implications were formulated and presented in the discussion and conclusion of this study. Each of the different elements outlined in the study design above are expanded on in the sections below.

### **3.3 Theory identification**

An important first step in the case study approach was to make explicit the theoretical context of the study. As previously detailed, the concept of integration is unclear, and there is little research demonstrating how integration in the context of self-management is experienced and perceived by patients and HCPs in a natural setting. The theoretical proposition for the case study approach follows the theory of CAS and the conceptual model for integration outlined in Figure 1-1. The framework makes explicit the theoretical assumptions for the study design, detailing the underlying structure of non-linear interactions within integration; and combines it with the key components of integration in relation to self-management education, as previously presented in Figure 2-2.



It is important to note that while this theoretical model informed the design, it was not intended to constrain any novel understandings. The intention was for the model to guide the inquiry while not predetermining the sphere of observation. The model was explored and expanded by being examined in a natural setting with a whole-system approach.

### **3.4 Case selection within the context**

In this section, the case selection and context are outlined. A recent national survey provides a comprehensive overview of integrated care delivery in Switzerland (Ebert *et al.* 2015). Of the 44 integrated care initiatives identified in the survey, one initiative contained all components relevant to the integration of self-management education, as conceptualised in Figure 2-2. Therefore, the Cantonal Diabetes Programme (PcD) in the canton of Vaud in Switzerland was selected for the study.

The Cantonal Diabetes Programme is comprised of over 40 projects (see Appendix II), and much of the programme was outside of the scope of this research. Therefore, projects focusing on patient self-management were scrutinised for inclusion in the study. To meet the selection criteria, the self-management education had to involve explicit areas of integration (as defined in the theoretical model) and activities for patient self-management education. Moreover, it had to be delivered by interdisciplinary teams who could interact across different settings of care or within the same care system.

Five programmes were potentially eligible for inclusion. Of these five programmes, three were purposefully selected to address the research questions and to directly observe the components of integration interacting in context. The criteria for selecting the cases were justified in relation to the representation of the theoretical proposition (Stake 1995, Yin 2009) presented in Chapter 1 and based on the theoretical model outlined in Chapter 2.

Two of the programmes addressed patients directly and involved the integration of multidisciplinary healthcare teams and peers in self-management education. The other

programme focused indirectly on patients by integrating the training of HCPs in different settings in order to support patients' self-management. From the two programmes addressing patients directly, interactions between HCPs, peers and patients were explored in the context in which care was delivered. The programme that indirectly addressed patients allowed a theoretical exploration of different care approaches to self-management education. The sections below provide summaries of each case:

**a) Case A**

The co-led self-management programme is also called “becoming the actor of your own health with chronic disease” (Deppeler 2015, Haslbeck 2015). It is a linguistically and culturally adapted version of the Stanford chronic disease self-management programme developed by Lorig *et al.* (2012). The programme's objectives are to improve self-management behaviour through increased self-efficacy and to foster the confidence required to achieve a specified goal. The self-management intervention consists of six weekly, structured workshops that trained and certified peer educators and diabetes specialist nurses, dieticians or other HCPs collaboratively deliver. The programme aims to enhance the self-confidence of people living with chronic diseases by encouraging them to discuss theoretical inputs and exchange individual experiences.

**b) Case B**

This 12-week rehabilitation programme for people with T2DM and cardiovascular risk factors consists of physical activity sessions and themed workshops on disease, risk factors, medical therapy and nutrition as means by which to enhance lifestyle changes (Saner & Diem 2012, DIAfit 2016) . The programme combines theoretical knowledge and active participation in physical activity: at least three 1-hour sessions per week with physical activity and six to eight group lessons with theoretical inputs over 12 weeks in addition to two individual

consultations (Société suisse d'endocrinologie et de diabétologie 2010). Trained and certified HCPs and sports therapists deliver the intervention collaboratively in the form of group education (University Bern 2015). The programme aims to facilitate active participation in physical activity, to enhance theoretical knowledge and to enable participants to exchange their experiences.

**c) Case C**

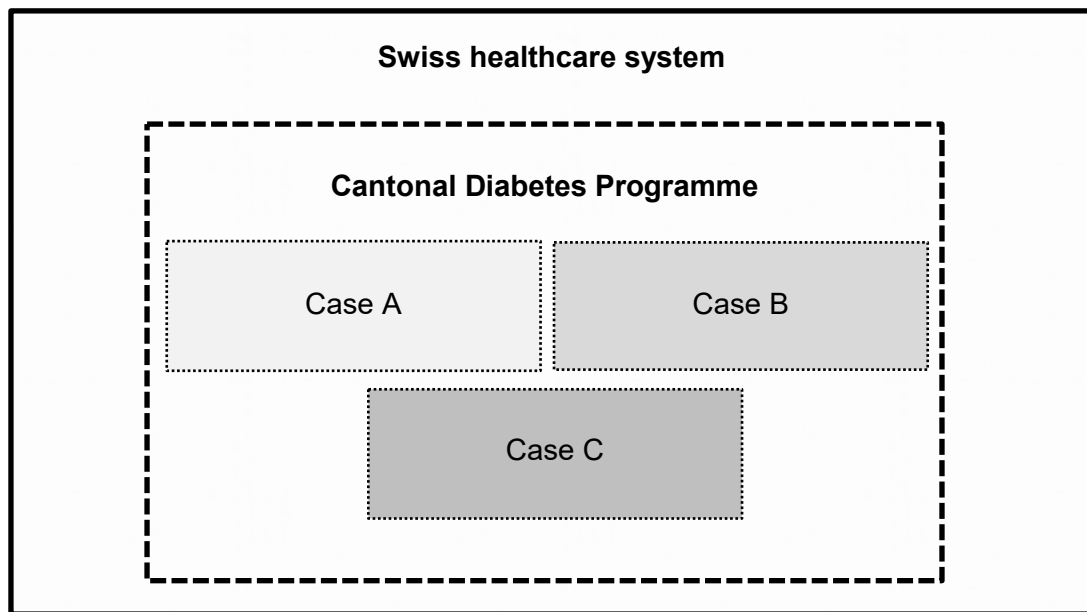
This programme, which raises awareness regarding therapeutic education among healthcare teams working in primary care (Sofra *et al.* 2014), is collaboratively delivered by HCPs trained and certified in therapeutic patient education together with experienced practitioners. The trained HCPs have graduated from a 2-year postgraduate programme in therapeutic patient education (University of Geneva 2015). The collaborative approach used in the three half-day awareness courses (12 hours total) targets different HCPs in primary care, aiming to raise their awareness regarding the treatment of patients with chronic disease and to make them more familiar with the means and models used in therapeutic patient education (Programme cantonal Diabète 2016b). The programme aims to support patients' self-management behaviour by improving HCPs' understanding of the care approaches used in therapeutic patient education.

The cases consist of self-management education programmes that contain the components of integration identified in Chapter 2. The programme characteristics and different levels at which these components can be observed are summarised in Table 3-1.

**Table 3-1** Programme characteristics related to integration of self-management

Components of integration	Case A	Case B	Case C
Interpersonal relationship	HCPs; peer educators; patients	HCPs in inter-disciplinary teams, including physio- and sports therapists; patients	HCPs trained in therapeutic education; HCPs working in primary care and related professions
Programme ethos	Group exchange of patients' personal experiences to increase self-efficacy	Group training combined with theoretical input to encourage physical activity	Awareness-raising training of HCPs on therapeutic education to enable patient self-management
Shared learning	Exchange groups of personal experience of living with chronic disease	Training groups to increase level of physical activity and understanding	Develop vision of self-management (in care networks)
Adapting to context	Linguistically and culturally adapted delivery of structured self-management education	Training programme adapted to individual physical conditions	HCPs skills and awareness training adapted to needs
Care system organisation	Cantonal; national; international	Cantonal; national	Cantonal

Detailed case descriptions are presented in the case reports in chapters 5 to 7. Within these cases, the components of integration considered include their manifestation and interactions at the levels of the patient, HCP and system. Each case was regarded as an individual unit in order to identify mechanisms that may determine how integration was expressed in each case. Thereafter, the cases were considered across all cases to reflect on how integration may be mediated through factors impacting on self-management education programmes within the context of the study. The cases were embedded in the context of the PcD within the overall Swiss healthcare system (see Figure 3-2).



**Figure 3-2** Embedded case design, adapted from Yin (2009)

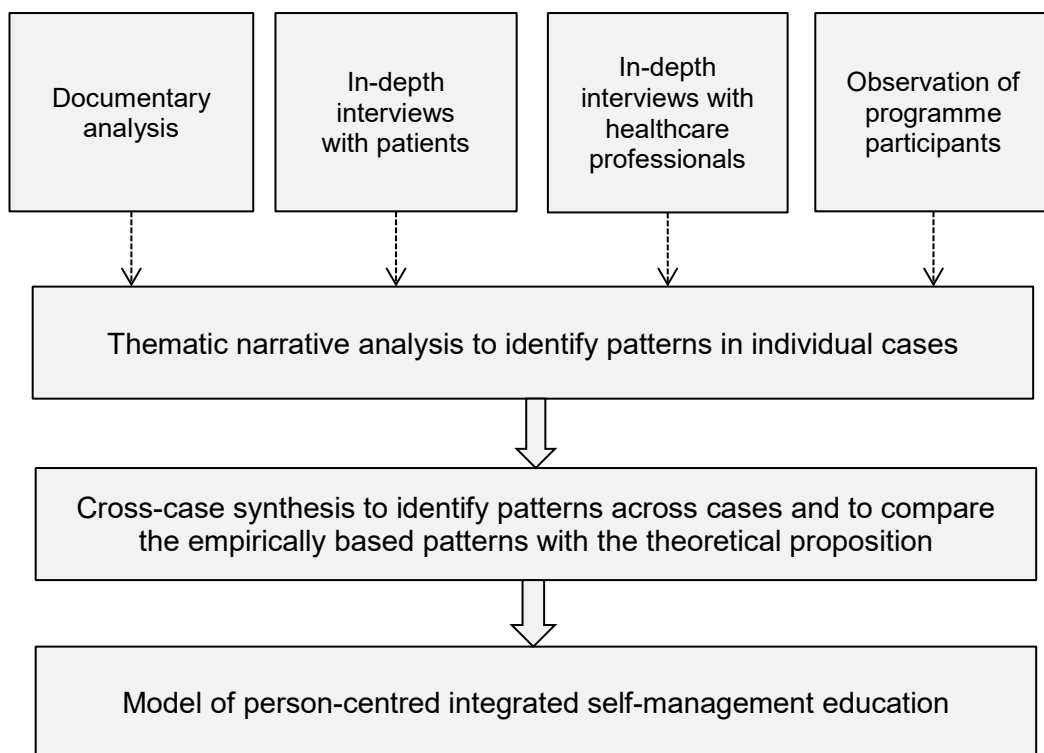
According to the embedded case design approach used for this study, the cases were analysed in light of their contextual factors. The dotted lines that separate the cases from the context of the Swiss healthcare system suggest that such boundaries are unlikely to be definite and the interactions may cross these boundaries (Yin 2009).

In the next section, the data collection methods and procedures are defined in order to address the research questions in the case study design.

### **3.5 Case study overview**

As previously detailed, the case study approach requires multiple forms of data collection. This section provides an overview of data collection sources and how they were integrated and analysed in the narrative-based case study design. The data from the in-depth interviews with patients and HCPs, the field notes from the participant observations and the documents were analysed using the thematic narrative approach (Riessman 2008). Within this approach, the data were analysed in order to understand individuals' experiences (represented by people's stories) and the relationship between those experiences, the context observed and the purpose (identified in the documents).

Participants' narrative knowledge helps to make sense of the ambiguity and complexity of their experiences within the case context. The case descriptions organise the general characteristics of the data and identify patterns that emerged from each case. These patterns were synthesised across the cases and compared to the theoretical propositions that initially formed the design of the case study research. The analytical and synthesising processes developed the model of person-centred integrated self-management education. The flowchart of different phases is presented in Figure 3-3.



**Figure 3-3** Flowchart of phases of data collection, analysis and synthesis

The model of person-centred integrated self-management education is presented in Chapter 8. The subsequent sections of this chapter detail the role of the project advisory group, data collection instruments, sampling and recruiting of participants, field procedures used to negotiate access to the sites and data synthesis.

### **3.6 Project advisory group**

In keeping with the case study research design, it was important to include multiple perspectives that represent different views to be able to understand and interpret the phenomenon in the specific context (Yin 2009). Therefore, the study design and the design of the data collection tools were informed by consultation with expert advisory groups. Their role was to ensure the relevancy of the interview topics and to give feedback on the research. Two advisory groups of experienced diabetes specialist nurses and interdisciplinary diabetes team members informed the design of the data collection form and the development of the case study protocol. Moreover, patients gave advice regarding the clarity of the questions asked in the semi-structured interviews and of the data collection forms. These advisory groups are presented below:

- a) The diabetes specialist nurse group consisted of five people who were recruited from members of the executive committee of the national organisation of diabetes specialist nurses. They were consulted after ordinary scheduled committee meetings in January and March 2015.
- b) The interdisciplinary advisory group consisted of seven people with different professional backgrounds whom the researcher contacted individually based on recommendations and their expertise.
- c) Two patients, not participating in the study, were purposively sampled based on their experience of living with diabetes for more than 5 years.

The group members received study information and were asked to provide feedback on the interview topic guides and data collection forms. The group met either virtually (via email discussion) or in person, depending on the individuals' preferences and availabilities. The protocol was discussed with the supervisors and a key person from the advisory group.

### 3.7 Recruitment and sampling

Each programme was delivered in multiple sites at different occasions in either urban or rural locations. Two study sites per programme were purposively selected to access a diverse population of participants from whom to recruit. The sampling frame for recruiting participants was based on the criteria set out in Table 3-2.

**Table 3-2** Sampling frame with criteria for recruitment of participants

	Number of healthcare centres (n)	Programme receiver (Participants)	Programme deliverer (Main disciplines of HCPs)
Case A	3	Patients with T2DM and other chronic diseases	Diabetes specialist nurses, dietitians, peer educators
Case B	8	Patients with T2DM and cardiovascular risks	Sports therapists, physiotherapists, dietitians, diabetologists, diabetes specialist nurses
Case C	4	HCPs in primary care and related areas	HCPs certified and experienced in therapeutic education
Total	15	Sampling until data saturation reached	

The sample consisted of patients and HCPs who participated in one of the three cases, thus making it possible to explore their perspectives and experiences of integration related to their programme.

#### *Programme receiver*

In cases A and B, patients were eligible for study participation if they were older than 18 years, diagnosed with T2DM and currently participating, or had participated within the last two years, in a self-management education programme in either an urban or a rural setting. In Case C, HCPs were eligible for inclusion if they participated in the awareness-raising programme and worked in primary care or related areas, such as general



practitioners, pharmacists, physiotherapists, dieticians, diabetes and other specialist nurses, podiatrists and professional assistants.

#### *Programme deliverer*

Healthcare professionals were eligible for study enrolment if they had experience with the programme delivery in one of the cases.

#### *Exclusion criteria*

For patients, the exclusion criteria were serious physical or mental illness or being unwilling or unable to give consent.

For HCPs, the exclusion criteria were not participating in programme delivery in one of the cases or not being willing to give informed consent.

Patients were screened for these inclusion and exclusion criteria and identified through their HCP, who was either a diabetologist, general practitioner, diabetes specialist nurse, dietician or physiotherapist. Information leaflets were given to all potential participants, and if they provided informed consent, they were invited to talk to the researcher for further information and to arrange a meeting for the in-depth interview.

The researcher identified potential HCPs and asked them to participate in the study. If they provided informed consent, they were invited to participate in either individual or group interviews, considering their personal preferences and availability.

The sampling of the participants was purposive in order to capture the diversity of experiences and perspectives regarding integration within each programme of self-management education. In each of the programmes, participants were recruited until the point of redundancy was reached (Guest *et al.* 2006). Therefore, the sample size was ultimately determined by data saturation, which occurred when the data became repetitive, with no new or relevant information being added with respect to exploring of the theoretical conceptualisation (Shenton 2004, Morrow 2005, Bowen 2008).

### **3.7.1 Access to study site and participants**

Study site access was negotiated by approaching the staff members responsible for the programme in each centre. The individual participants were contacted once site approval was obtained. The research project was presented to the executives of the Cantonal Diabetes Programme (PcD) on 9 April 2015 and to stakeholders of the Public Health Service of the canton of Vaud on 9 June 2015. Through this involvement, the study project was acknowledged. This support eased access to study sites and participants. Formal ethics approval was applied for and received. A fuller description of ethical considerations is provided in section 3.14.

## **3.8 Data collection instruments**

The instruments were developed based on the conceptual model previously outlined and were informed by the advisory groups. The interview topic guides, observation guide and data extraction tool for documentary analysis underwent consultation and piloting:

- a) The discussion with the diabetes specialist nurse group led to first adaptations, which were mainly related to different interpretations of integration in relation to self-care and self-management.
- b) The second consultation phase with the interdisciplinary diabetes team guided further contextual adaptations. The changes were principally related to inter-professional clarifications of the meanings of integration in different contexts.
- c) The semi-structured interview topic guide for patients was then piloted with two patients, who were not participating in the study. The same approach was taken with the semi-structured interview topic guide for HCPs, which was piloted with a team of HCPs not participating in the study.

These pilots allowed for feedback and for checking timing and feasibility. As a result of the feedback, the interview topic guides were shortened, and the questions were

rephrased. For example, the term “integration” was clarified by using expressions that explained it more specifically and by asking about patients’ experiences with particular HCPs and with the delivery of care they had received. While the participants may have understood the term “integration” in slightly different ways, they nevertheless were relatively clear on what the concept should entail (Walker *et al.* 2013). After revising the data collection instruments, they were discussed a final time with the interdisciplinary advisory group. A compendium of the data collection tools used in the study is presented in Appendix VIII.

### **3.9 Data collection procedures**

The data collection procedures consisted of four different qualitative data collection methods: a) interviews with individual patients, b) interviews with HCPs, c) participant observations and d) documentary analysis of programme documents. Descriptive data detailing the characteristics of participants were also collected.

#### **3.9.1 Interviewing participants**

As the programme participants acted as informants for the cases (Yin 2009), the semi-structured interviews focused on participants’ experiences and perceptions of integration within the confined frame of their programmes. In all semi-structured interviews, open-ended questions were used to allow interviewees to answer freely about their experiences and to tell the story of how they perceived their programme to be integrated into care delivery (Britten 1995, Witzel & Reiter 2012). The in-depth interviews were audio-recorded and transcribed verbatim. Field notes about the interview situation and interactions were taken directly after each interview and summarised in a reflective log. An example is provided below in Vignette 3-1.

### **Vignette 3-1 Healthcare professional interview (Bertrand<sup>1</sup>, Case B)**

One of the interviewees had to reschedule his interview, and, as a result, I had three interviews booked for the same day: one in the morning and two in the afternoon. I had blocked one and a half hour for each interview, but I was worried that one of the interviews may take longer, causing me to be late for the next.

The morning interview, which took place in the consultation room, started as planned on time, and I began by asking the first interview question. After 8 minutes, the phone rang, and the interviewee, Bertrand, answered the call. I immediately stopped the recording when the phone rang. The call was short, but it nevertheless interrupted the interview flow. I made a short summary and reformulated the already asked questions that I recorded before continuing with the interview. After another 15 minutes, he was called again and needed to see someone urgently, so we rescheduled the interview for later in the day. I left the room and sat down in a quiet corner to summarise how the interview had gone so far. He had only answered the first two questions, and I felt that there was much more information that he could give me.

I thought about rescheduling the other two interviews, but Bertrand returned to the office shortly after. He apologised for the interruption and said that he could continue the interview for another 30 minutes. He transferred his phone calls to his secretary so that there would be less disruption. I thanked him again for taking the time and restarted the interview by recapitulating the first questions. He answered the questions in a much more detailed way, such as how the interdisciplinary colloquium was organised and expanded in order to also invite HCPs from primary care. I took on an affirmative body posture and only murmured affirmations so as not to interrupt him. At the end, the interview length was over 40 minutes, and I received excellent answers to my questions, which I had asked only in the form of prompts.

Although the beginning of the interview with several interruptions went poorly, restarting with summarising questions was helpful and contributed to the detailed responses I received. While listening to the recorded interviews, I also noticed that the pace in his voice was more relaxed in the second part of the interview. Because I had planned enough time between the interviews, the time reserve allowed for this unforeseen event, and the following interviews went as planned.

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<sup>1</sup> All names used in the field notes are pseudonyms.

***In-depth interviews with patients:*** The in-depth interviews were conducted with patients who had experienced self-management education. Topics explored included patients' understandings and experiences of how the education was integrated in their routine care, the HCPs involved, the support they received and the integration of self-management behaviour into their daily lives. The final version of the topic guide can be found in Appendix IX.

***In-depth interviews with healthcare professionals:*** The interviews were used to examine the views of the interdisciplinary team members delivering the programme of self-management education (including peer educator, if applicable). The interviews focused on HCPs' experiences and perspectives of integration and explored integration in the delivery of self-management education among HCPs. The data were collected individually and on one occasion (for organisational reasons) in a small group of three participants who regularly interacted by working closely together. Topics covered included HCPs' understandings and experiences of integration in current self-management delivery, the experiences and meanings given to collaboration and care, and the perceived self-management support given to patients within the present system. The final version of the topic guide is in Appendix X.

### **3.9.2 Documentary analysis**

Because accessible and regularly updated documents give reliable information, information resources that pertained to the programmes being studied were collated and summarised. These included programme descriptions and, where available, curricula; support materials (leaflets, handouts, work documentations); cantonal guidelines and recommendations. Documents were screened for their relevance to integration. Data were extracted using the data extraction instrument (see Appendix XI). Data were collected regarding type, content and purpose of the document, its referencing of other

documents, its authorship and readership, and the structure of the document. An overview of the documents considered is given in Table 3-3.

**Table 3-3** Documents used as information resources in documentary analysis

Level of integration	Documentation
Programme	Programme descriptions and, where available, curricula Support materials: leaflets, handouts, work documentations
System	Guidelines and recommendations

### 3.9.3 Participant observations

The researcher observed up to six sessions of self-management education, in each case following an observation guide (see Appendix XII). While an important advantage of observation is that it may discern between what people say and what they actually do, informing participants about the research before observing them may also alter their behaviour (Mays & Pope 1995a, Polit & Beck 2012). The observational data included field notes on the context/environment (e.g. who, where, when, why and for what purpose), which were collected prior to the observations, and logs on the research focus, which contained notes on the collaborative roles of programme deliverers, the active participation of patients and the communication style used during the observation. These notes were reviewed immediately after each session and used to make adjustments for the following observation (Van Maanen 1979). These modifications ensured that different aspects of participants' interactions were covered during the observations. All observations and field notes were kept in a log book. Observations took place in the entire group but focused only on certain aspects within each session, such as who spoke and the number of interruptions.

### **3.9.3.1 Role of observer**

In this section, I describe how I situated and presented myself as a participant while observing the programme. It is commonly assumed that being an insider participant-observer facilitates access to participants and offers a better understanding of the cultural context. However, these advantages are not unconditional; furthermore, it is essential to address ethical and methodological issues that might arise from being an insider (Bonner & Tolhurst 2002, Labaree 2002, Mercer 2007, Taylor 2011, Kennedy-Lewis 2012).

I fully described the nature of the study to all participants and always disclosed my credentials and professional background. It may be that some participants consequently distorted their behaviours or responses during observations. However, I observed multiple sessions with different HCPs and patients in different settings over a nine-month period, collecting a broad variety of data over the full length of the programme. This prolonged engagement helped me recognise distortions and ensured data saturation of the key themes. To control for my subjectivity, I maintained a reflexive journal to help me to recognise my own biases and assumptions. These introspective processes helped me understand how my experiences and beliefs were part of the study; in addition, I discussed my emergent interpretations with some participants in debriefing sessions, other researchers and supervisors.

In the present study, there was no observation of bad practice; if bad practice had been observed, the supervisors would have been informed, and the appropriate procedures would have been taken relating to the practice.

My professional network and presentation at the PcD facilitated contact with HCPs and study sites. Although I was familiar with the PcD, I had never been directly involved in it or in the delivery of any of the observed programmes. Before observing a programme, I

considered how my own perceptions might influence the data collection and wrote these down on a separate sheet in my notebook. While presenting my research project to all participants, I consistently introduced myself as a researcher and emphasised my role as a participant-observer. It was clear that I was not involved in the delivery of the self-management education programme in any way other than participant observation and that I was not implicated in any aspect of the patients' clinical treatment. I did not recruit any participants that I was formally working with.

In all observed programmes, rapport with participants developed quickly and trust was established. Nevertheless, my presence as a researcher undoubtedly influenced the setting. Participants showed interest in my research; in some sessions, some even discussed different aspects of integration and how they related integration to their personal disease integration in a manner that influenced their behaviour. This occurred mostly during breaks and after the session. To validate their experiences more formally, I invited the participants who had offered these relevant comments to participate in an in-depth interview. Prior to doing this, I informed the group leader of each programme that I planned to recruit participants from the programme, and the leaders agreed to my approach.

All programmes were highly interactive, and I focused on my role as an observer by using active and reflective listening skills (Miller & Rollnick 2009, Rogers & Farson 2015). Observational and methodological notes were taken, mostly as short notes or bullet points, and complemented immediately after the session with more expansive reflective notes about my own position during the session. Although I do not claim that I entered the study devoid of opinions and values, I was open to new ideas and contradictory perceptions. I was prepared to challenge my understandings with opposing thoughts and to supplant my current perceptions of self-management with new insights and opinions derived from the observations.



Vignette 3-2 and Vignette 3-3 are examples of reflective logs, combining the field notes from the observation and information from the in-depth interviews.

### **Vignette 3-2 Participant interview (Susann, Case A)**

I first met Susann because she was a programme participant in one of the settings of case A. I noticed during the programme that she described her feelings in a detailed way. I observed that she participated actively in the programme and expressed her experiences openly, such as when she described that it was difficult for her to bring all her roles (family, work, hobbies) in line and that diabetes did not always have the place it should. She said that she used to feel guilty about that because many people in her environment often gave more importance to her disease than she did. In dialogue with other participants, she voiced the feeling that diabetes was only one part of her life and that it was okay that she had other priorities – just as others do.

After the end of the programme, I asked her to participate in the in-depth interview. I thought carefully about how to contact Susann because I knew she was busy with the various life commitments that she had described during the programme. So, I sent her an email asking for the best time to contact her and offering to come to see her at the most convenient place for her. She responded within two days and invited me to her home for the interview.

I was excited and also apprehensive that she agreed to participate. Before I left for the interview, I double checked the recorder and that all materials I used for the interview (interview guide, log book, study information sheet and forms to sign) were ordered in the work bag. During the interview, I used the interview guide as an initial prompt and to guide the interaction. Susann talked in-depth about these issues, and I did not need many prompts. Instead, I was concentrating on active listening and note-taking. However, because the note-taking was disturbing the flow of the interaction as well as my concentration, I reduced the note-taking to bullet points. I was happy that I had the interview recorded. While listening to the interview several times, I recognised that I had interrupted her a few times with my questions. I wondered if I had missed anything by doing so and planned to pay more attention to not interrupting my interview partner in the next interview.

Vignette 3-2 is a reflection on the field notes of the observations and patient interview conducted in Case A. This reflection helped me pay more attention to listening and to recognise the importance of an undisturbed interview flow. In the interview phase, I took field notes (again, mostly in the form of bullet points) for two reasons: They helped me to keep track of important aspects in the interview, and they enabled me to become more aware of my own perceptions. Throughout the research process, I made notes on my own perceptions and wrote those down separately to avoid conflating my perspectives with those of the interview participants. After each interview, I asked the interviewees off the record what they thought about my perceptions; for example, I perceive self-management education and support as essential for self-management behaviour. Two interviewees opposed that perception for different reasons, which are further elaborated in the case reports.

In all cases, at the end of each programme, an after-programme meeting was organised by the programme group leaders in the form of a longer coffee break, an informal gathering or a dinner. I used these informal occasions to discuss some of the preliminary findings with some of the participants – both patients and HCPs. They provided supportive suggestions for how to refine the interpretation, and some advised specific ways to clarify the content of the components of integration. Such examples are illustrated in the case reports in chapters 5, 6 and 7.

Another example of a reflective log is provided in Vignette 3-3. This log reflects on the observational field notes and HCP interview in Case C.

### **Vignette 3-3 Healthcare professional interview (Claire, Case C)**

Claire was one of the programme leaders, and I noticed during the programme observation that she often used encouraging expressions voiced in a warm tone. At the end of the programme, I invited her via email to participate in an in-depth interview. She responded the same day and affirmed her willingness to be interviewed. She told me that her medical office was near the main train station and that because the entrance was often closed, I needed to ring the bell for access. I felt excited about the interview and the opportunity to ask her about her experiences of integration in therapeutic education. When I arrived, I was pleasantly surprised because I had expected an environment in which entrances needed to be closed for safety reasons during daytime. It was a clean mixed residential area, with mostly renovated buildings. When I rang, the door opened immediately.

Claire welcomed me and invited me to her office, where she offered a place to sit down. She then positioned her chair so that we could easily speak to each other without talking across an office desk. It was also an examination room, but it was furnished in a homely way with friendly colours, wooden floors, curtains and pictures on the wall. I felt a bit like being in someone's living room. I did not immediately see a computer and when I asked her about that at the end of the interview, she said that she wanted to give the information technology a less dominant place in her consultations because her main instrument was interpersonal interactions and patient conversation, but of course she also used a computer.

This interview was more of a dialogue in which I used my questions as prompts. When I listened to the recorded interviews, I noticed that she frequently made small questions and comments to make sure I understood. I did not immediately recognise that during the interview, but I felt that this conversation went smoothly and assumed that she likely talked the same way to other people too. Her conversational style did not alter the interview questions at all, but I felt that it added more depth. For example, sometimes she referred to examples from the programme sessions or mentioned situations from practice and related those to my questions. During the interview, I felt the same warm and supportive atmosphere that she created in her sessions. While listening to the recording, I learnt much from how she used words, expressions and tone and how those interpersonal traits influenced the conversation. Furthermore, my perceptions were influenced by little details and nuances that made me feel at ease in that environment.

#### **3.9.4 Data integration**

One of the challenges in this case study research was managing data collected from four different sources. These data were pooled into a common analytical framework in order to build data synergy. To this end, a study database was constructed, which was crucial for organising the material of the data sources (Yin 2009). The interviews were audiotaped and transcribed verbatim. The transcripts, field notes from interviews and observations, and documentary analyses were uploaded into a qualitative data analysis software programme (NVivo version 11) to ease data handling. The data were organised into individual case records that represented the data from each programme (Patton 2002). This made it easier to locate specific data for the coding and categorisation of each case. The case records were handled and annotated independently of the final case study report. All demographic data were organised in tables according to each case and kept separate from the interpreted case reports.

#### **3.10 Data analysis and synthesis**

The data from the interviews, field observations and documentary analyses were analysed to understand the concept of integration in the bounded context. Thematic narrative analysis (Riessman 2008) was used to analyse the data within the case study design. First, after providing a detailed description of the programme, each case was analysed as a comprehensive unit, and codes were categorised into sub-themes to identify unique patterns. The codes and sub-themes of each programme were then investigated using a pattern-matching logic in order to identify themes across the cases (Yin 2009). The patterns were searched for similarities and differences by comparing prior theory and data within the cases to develop an understanding of each programme and to explore processes and outcomes across the cases within the local context (Yin 2009).

Data collection was undertaken in the French-speaking part of Switzerland; thus, all interview data were in French, which introduced another difficulty to the project (further elaborated in section 3.13). Interview transcripts were read through several times to become more familiar with the context and content of each interview. Subsequently, each transcript was coded in segments, rather than line by line, in order to keep the narratives intact (Riessman 2008, Saldaña 2013).

The thematic narrative approach involved identifying and interpreting the narratives, or segments of the narratives, as they related to the components of integration at different levels in the specific context. In thematic narrative analysis, prior theory can guide interpretation of written and spoken material (Riessman 2008, p. 73), and the integrity of accounts is maintained by keeping text and context together (Riessman 2008).

The initial descriptive coding, using tree nodes and free nodes in NVivo version 11, was derived from prior theory and collected data. These analytical processes involved a combination of analytical induction from the sensitising concepts (*a priori* codes) and inductive analysis from the emerging understandings (Patton 2002). The *a priori* codes acted as an initial list to work with. The codes in the initial coding frame were inductively expanded to include the breadth of the study data, and new codes were added to the initial frame. They were then clustered into sub-themes and themes that enabled exploration of how different components of integration were apparent in the programmes as well as how those components were given meaning in the particular setting of each programme. An example of how the concepts identified from the literature developed the sub-themes is outlined with code descriptions and data excerpts from the patient interviews in Appendix XIII. The codes included segments of narrative text and linked memos, which included the context that led to the narrative, as well as any clarifications informed by other data sources (Riessman 2008).

At this stage of analysis, printing out all the codes helped to group the codes and sub-themes into themes. By using the themes as headings and organising the sub-themes and coding strips underneath them (*i.e.* seeing all data at the same time), the codes could be easily grouped and re-grouped. In that phase, the discussion with supervisors and colleagues furthered reflection and helped refine the clustering of the themes. The process of visualising the data helped to identify and describe the meaning of the abstract concept of integration as well as to reduce the data. The themes were relabelled to better describe their content, and the resulting changes were discussed with supervisors and other researchers. Examining and comparing the codes and sub-themes within and between themes allowed the stories of integration to emerge from the data. As a result of that process, the identified themes were co-constructed within the larger meaning of the narratives' context and interpreted integration in the context of self-management education.

The next step involved iterative tabulations of the different data sources to enhance the definition of each constructed theme. During the tabulation and interpretation phase, unique patterns in the cases were identified from the interview, observational and documentary data, which were then compared across cases. The cross-case synthesis tested whether the patterns and relationships within and between the constructs fitted with the evidence from the literature. This process involved exploring the data regarding how and why integration happened in the context. The interpretation of patterns and relationships in the cases developed the programme replication logic (Yin 2009). The replication logic in case study research relates to how the results of a case compare to other cases or theoretical propositions (Bergen & While 2000, Yin 2009). Following this approach, the synthesis identified the reasoning for reproducing the programme and therefore forms the bases for the logic model of person-centred integrated self-management education.

### **3.11 Theory modification**

The case study was guided by the theoretical proposition that dynamic non-linear interactions between components observed in self-management education programmes influence patient behaviour. Non-linear interactions in healthcare delivery has been previously described as representing a CAS (Holland 1992, Plsek & Greenhalgh 2001, Plsek & Wilson 2001, Wilson *et al.* 2001, Best *et al.* 2012, Clark *et al.* 2012). The present research expects that specific patterns and relationships relate to the behaviour resulting from the interacting components of integration in the context of self-management education and therefore emerge from such non-linear interactions.

The modification phase involved considering the emergent findings from the case studies and revising and extending the theoretical propositions developed from the conceptualisation phases outlined in chapters 1 and 2. The different perspectives considered during the phase of theory modification further sharpened the logic model, enabling better understanding of integration in relation to self-management education. The implications for programme integration and delivery were derived from these interpretations (see Chapter 9).

### **3.12 Case reports**

A separate case report was written for each case based on the evidence identified in the data sources. The source data were analysed with deductive and inductive reasoning according to the theory-building structure and synthesised into the case report (Eisenhardt 1989, Yin 2009). The case reports are presented in Chapter 5 (Case A), Chapter 6 (Case B) and Chapter 7 (Case C), respectively.

All case reports were then integrated into the cross-case synthesis. The cross-case synthesis expanded the model of person-centred integrated self-management education and is conceptually linked to the theoretical and empirical evidence. The cross-case synthesis and model are presented in Chapter 8.

### 3.13 Translation

This study is of a multilingual nature because data collection and analysis were undertaken in their original language, French; key findings and supportive evidence were then translated into English (Esposito 2001). The process of meaning-based translation involved translating from French into English and then translating that English translation back into French (Brislin 1970). This was undertaken by two bilingual people familiar with self-management education. After translation, the translators and researcher compared and discussed the two texts, and some members of the advisory groups checked for comprehension, readability and consistency of meaning (Regmi *et al.* 2010).

While this process was adequate for translating the study forms, it introduced difficulties for analysing and presenting the interview data. The data explored perspectives and experiences of the integration of self-management education and involved interpretations of participants' narratives. As a result of the translation process, the meaning of the accounts was not always fully reflected as intended in the original language. This is a common problem in translating because nuances or colloquial expressions can be lost or cause confusion in another language. Interpretation depends on the language researchers use in a particular context because different verbal behaviours in different languages influence interpretations (Larkin *et al.* 2007, Temple 2008, Choi *et al.* 2012). For example, some translated narratives seemed to lack the essence of the meaning when translated, or their meaning was altered when back-translated into the original language. To address these issues, the translations of some interview excerpts were discussed with a Royal Literary Fund writing fellow at King's College London who was fluent in the same languages as the researcher. While this process supported the data analysis and interpretation, it was limited due to the writing fellow's restricted availability. The researcher and supervisors thus decided to involve



professional translators to stay as close as possible to the original narratives. Some of these excerpts were used to illustrate the study findings in the case descriptions.

### **3.14 Ethical considerations, data handling and data protection**

The ethics documentation was submitted jointly by the Institute of Social and Preventive Medicine of the University of Lausanne, the Cantonal Diabetes Programme and King's College London. The study received ethical approval (protocol number 237/15) from the Cantonal Ethics Committee on Research Involving Humans of the Canton of Vaud (CER-VD) in Switzerland in July 2015 (see Appendix XIV). Swiss ethical approval was acknowledged by the Research Ethics Committee of King's College London (see Appendix XV). The study commenced immediately after ethical approval was received.

Ethical issues may be pertinent in every stage of the research process and may relate to the potential study benefit, respect of human dignity and justice (Orb *et al.* 2001, Polit & Beck 2012). In this study, there was no direct benefit for participants, but their contributions helped others with similar problems. They participated voluntarily after full disclosure, and their autonomy was respected, and their privacy maintained. The ethical issues were addressed in the respective study phases.

All programme participants were informed using the study information leaflet for HCPs (see Appendix XVI) or the study information letter for patients (see Appendix XVII). Potential participants received sufficient time to decide whether to participate in the study, and it was made clear that there was no obligation to participate. Participants were invited to ask questions prior to participating and were told that they had the opportunity to withdraw at any stage of the research process without any fear of repercussion. All participants were asked for verbal and written consent (see Appendix XVIII). Confidentiality was maintained throughout the study and continued after completion. The interview transcripts, field notes, observational notes and any other information related

to the study were stored in password-protected computer files and securely locked in filing cabinets. Identifiable and personal data were removed, and all personal information was anonymised. In the field notes, participants were referred to with pseudonyms. Only unidentifiable data were used in the study and in the distribution of study findings.

Participating in interviews takes time away from the day-to-day responsibilities of HCPs and patients. Therefore, the interviews were scheduled at the convenience of the participants. While this study had no direct risks, talking about individual experience may have been unpleasant for participants at times. Although no interviewee became upset in the present study, if an interviewee had become disturbed upon discussing certain issues, the interview would have been stopped immediately and the interviewee would have been referred to an appropriate HCP for immediate support if further assistance was required.

### **3.15 Trustworthiness in qualitative research**

Establishing the trustworthiness of qualitative studies is an essential but challenging part of the research process because no established agreement exists regarding the standards with which to assess qualitative studies and because many perspectives and strategies exist with which to ensure methodological soundness and quality (Angen 2000, Tobin & Begley 2004, Rolfe 2006, Polit & Beck 2012).

In qualitative research, *rigour* relates to the systematic and self-conscious process in which the study was conducted, including the methodology and methods chosen for collecting, analysing and presenting the data used to address the study questions (Mays & Pope 1995b, Barbour 2001, Tobin & Begley 2004, Fereday & Muir-Cochrane 2006, Polit & Beck 2012). However, this is not a quantifiable process as in quantitative research; instead, rigour is determined via an explicit description of the rationale behind

decision-making and by an innovative interpretation that makes the process visible to the reader (Mays & Pope 2000, Polit & Beck 2012).

In thematic narrative-based case study design, the framework developed by Lincoln and Guba (1985) may help to establish trustworthiness. The criteria of that framework address four concepts – the study's credibility, dependability, transferability and confirmability – to show that a study's findings truly reflect the content and context presented by the participants. In this study, efforts were made to ensure trustworthiness by addressing these four criteria.

To address these criteria, different strategies are included in the study. Reflexive journaling was used throughout the study to guard against personal bias in making judgements (Pillow 2003, Shaw 2010, Polit & Beck 2012). Triangulation of multiple data sources and data collection methods were used to capture a more complete picture of the phenomenon (Lincoln & Guba 1985, Patton 1999, Polit & Beck 2012). Following these strategies, the evidence was gathered from in-depth interviews, participant observations and documentary analyses. These multiple means revealed the complexity of the phenomenon, facilitated cross-checking of the nature of integration and provided an opportunity to evaluate the extent to which a consistent and coherent picture emerged in the context. The study findings were supported by different data extracts, as documented in the case reports. This approach provided accounts of participants' realities as they perceive and experience the integration of self-management education in routine care.

The study followed a clear process of data collection and analysis, and the study protocol was discussed beforehand with members of the advisory board and supervisors. The researcher coded the data, while another researcher coded a small sample of interview transcripts, following a codebook. The researcher developed the codebook and discussed it with members of the advisory groups and supervisors. No formal process

was undertaken to gather feedback from every study participant. However, the interpretation of the concepts was discussed with some participants, other researchers, members of the advisory groups and supervisors. The study design was based on the theoretical propositions that are described in Chapter 2 and subsequently explored in the cases. This process is known as *analytical generalisation* and can be used in single or multiple case studies (Yin 2009, p.42). Analytical generalisation involves using a previously developed theory as a template to which the empirical results of a case study are compared. As Polit and Beck (2010) specified, analytical generalisation is initially to theory, and not to population or other cases. This is in contrast with external generalisation in quantitative studies, which are concerned with extending research results from controlled conditions and samples to the population as a whole using statistical inference (Maxwell & Chmielecki 2014).

In qualitative case studies, the transferability of findings to other cases depends on the detailed description of the case. As Yin (2009) and Bryman (2012) advocated, generalisation in case study research follows a replication logic rather than a sampling logic. The transferability can be strengthened if a case study is replicated in different circumstances and when the findings are related back to the literature (Dooley 2002, Yin 2009, Bryman 2012). This study explored the theoretical concept of integration in three different cases. The multiple case studies were conducted within one healthcare context, in which the emerging patterns from the individual programmes were compared to theory and analysed for replicability between cases within the same cultural and linguistic context. However, the logic model was not replicated in cases with different contexts; therefore, the cases have limited external transferability. As Erickson (2012) argued, particular causal processes may be at work in a certain local setting, but these specific mechanisms may manifest differently in other settings due to different local, social and cultural environmental factors. To attend to this matter, a detailed case description was provided for each case study to allow the reader to make a decision regarding the

transferability of each case to other cases. This is also called *reader generalisation* (Polit & Beck 2010).

### **3.16 Summary**

The preceding chapter provides an account of why a qualitative case study methodology with a thematic narrative-based approach was best suited for addressing the research questions. It also describes how the different methods were used to meet the overall research aim and study objectives. The rationale behind the case selection is outlined, the case study protocol defined, and an overview of the data collection methods and procedures given. The data analysis plan and follow-up modifications within the case study design are also described. The chapter finishes with a critical reflection on the quality of the study.

The study findings are presented below in five separate chapters, beginning with an overview of cases and participant data, followed by cases A, B and C. Finally, to answer the research questions, the cross-case synthesis and model of person-centred integrated self-management education are presented.

## Chapter 4 Self-management education programmes

This chapter is the first of five results chapters and presents findings that describe and contextualise the programmes and participants' data from the study cases. The data were collected in the context of three self-management education programmes from within the PcD, as previously described in Chapter 1. Each programme had different foci and employed different methods to enhance patient self-management.

This chapter starts with an overview of the data, followed by a detailed description of the participants and a presentation of the other data sources according to the case study methodology. The samples that formed the case studies were drawn from two study sites in each programme. The three cases were as follows:

**Case A: EVIVO**

Title: "Promoting self-management –  
Living healthy and actively with a chronic disease"  
(*"Promotion de l'autogestion –  
Vivre sainement et activement avec une maladie chronique"*)<sup>2</sup>

**Case B: DIAfit**

Title : "Diabetes rehabilitation programme"  
(*"Programme de réadaptation diabète"*)

**Case C: Therapeutic Education Awareness Programme (TE-AW)**

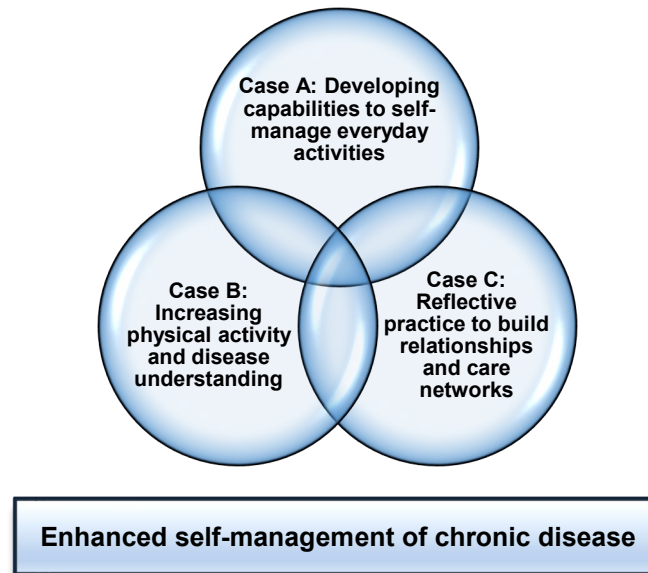
Title: "Raising awareness of professionals on therapeutic education"  
(*"Sensibilisation des professionnels à l'éducation thérapeutique"*)

Cases A and B focused directly on patients' self-management behaviours, whereas Case C indirectly operated by enhancing the skills of HCPs to improve self-management

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<sup>2</sup> Original French title in italic font and brackets.

support for patients. The different strategies used to enhance self-management in each case are summarised below and in Figure 4-1.



**Figure 4-1** Strategies used in self-management education programmes

In Case A, the focus was on strengthening patients' self-management capabilities to handle the everyday activities of living with chronic disease. These courses were not disease-specific and included people living with many kinds of chronic conditions, although many of the participants had T2DM. People affected by chronic conditions have to deal with many common challenges, such as regularly taking medication, adapting their nutritional intake to their physical needs or learning to live with an altered health condition. Therefore, in Case A people with different chronic diseases came together to discuss their individual experiences and challenges. A person living with chronic disease (who functioned as peer educator) and an HCP jointly led the courses, using elements of observational and experiential learning to enhance participants' self-efficacy.

These courses followed a structured curriculum based on the principles of social-cognitive theory (Bandura 2001) and the concept of empowerment – both of which were adapted to health education for people with chronic disease (Wallerstein & Bernstein 1988, Feste & Anderson 1995).

In Case B, the emphasis was on increasing the level of physical activity in people with diabetes. The programme integrated structured, interactive learning sessions with actual physical training sessions in groups. Sports therapists and physiotherapists led the training, using activities that promoted muscle strength and physical endurance. Interdisciplinary healthcare teams delivered the interactive group learning sessions. This programme was disease-specific and integrated knowledge about type 2 diabetes with physical activities, using an experiential learning approach to increase participants' levels of physical activity.

Case C aimed to enhance HCPs' understanding and delivery of self-management support across their healthcare teams by reinforcing their awareness of and capacity to provide therapeutic education to people living with chronic conditions. One of the course's components was for HCPs' to reflect on their individual attitudes and beliefs and on how their perceptions may influence their therapeutic relationships with patients in their clinical encounters. Another aim was to develop care networks of HCPs who have a common understanding of and similar approaches to self-management. HCPs trained and experienced in therapeutic education from at least two disciplines jointly delivered the courses to all members of the interdisciplinary team, using a reflective learning approach to enhance participants' understanding of therapeutic education.

Each of these individual programmes was integrated within the whole PcD to foster a comprehensive health approach for improving patient autonomy and positive self-management engagement and behaviours.



#### **4.1 Overview of data sources**

The data were collected from four different sources in each case: semi-structured interviews with both programme deliverers and receivers, course observations with complete programme participation and programme documentation. “Programme deliverers” refers to the HCPs and peer educators involved in the delivery of the programme, and “programme receivers” refers to the participants receiving the programme.

The data collection phase ran over a period of nine months, from July 2015 to March 2016, using the processes described in Chapter 3. The collected data included 56 interviews with both programme receivers ( $n = 32$ ) and programme deliverers ( $n = 24$ ); 88 hours of observations, including complete participation in three courses; and analysis of programme documents ( $n = 14$ ). The interviews conducted in the programme receiver groups consisted of patients ( $n = 20$ ) from cases A and B and HCPs ( $n = 12$ ) from Case C. The programme deliverer group contained HCPs ( $n = 21$ ) and patients in the role of peer educators ( $n = 3$ ), of whom one was still in training; this patient was a qualified HCP with 40 years of personal experience living with a chronic disease and participated in the facilitator training courses. Interdisciplinary teams of HCPs delivered the programmes, with the involvement of peer educators in Case A. An overview of the different data sources in each programme is presented in Table 4-1.

The participant characteristics of programme receivers and deliverers of individual cases are described in more detail in the following sections. Details of programme observations in each case and the documents included in the analysis are also provided in this first findings chapter.

**Table 4-1** Overview of data collection in the three programmes

	Case A	Case B	Case C
<b>Study sites (n)</b>	<b>2</b>	<b>2</b>	<b>2</b>
<b>Total interviews (n)</b>	<b>16</b>	<b>20</b>	<b>20</b>
<b>Programme receiver group:</b>			
Patients	10	10	-
Healthcare professionals	-	-	12
<b>Programme deliverer group:</b>			
Peer educators	3	-	-
Healthcare professionals	3	10	8
<b>Interdisciplinary team members involved in programmes:</b>			
Diabetologist	-	2	2
Generalist	-	-	1
Pharmacist	-	-	1
Diabetes specialist nurse	2	3	3
Nurse with other specialisms	-	-	7
Dietician	1	2	1
Physiotherapist	-	1	2
Sports therapist	-	1	-
Podiatrist	-	-	1
Psychologist	-	1	-
Medical or pharmaceutical assistant	-	-	2
<b>Total observations (hours)</b>	<b>24</b>	<b>40</b>	<b>24</b>
Study site group 1	15	10	12
Study site group 2	9	30	12
<b>Documents (n)</b>	<b>4</b>	<b>4</b>	<b>4</b>
Programme descriptions, leaflets	2	2	3
Websites	2	2	1
Guidelines, recommendations	<b>2</b>		

## 4.2 Description of interview participants

The participants' demographic data are presented by case and grouped into programme receivers and deliverers. The descriptive statistics are presented first for the programme receivers and then for the deliverers; these statistics describe the characteristics of the interview participants in each case.

During the interviews, participants expressed their subjective views regarding the integration of self-management education and their personal experiences with self-management in the cases. The length of the interviews is presented in Table 4-2. The total duration of the interviews was approximately the same in all cases, although in cases B and C more, slightly shorter interviews were conducted. Over time, in all cases, the interviews became shorter and repetitive with little new information added, which was an indication of data saturation.

**Table 4-2** Length of interviews in cases A, B and C

	Interviews (n)	Median length (minutes)	Interquartile range (minutes)
Case A	16	53	49–68
Case B	20	40	34-57
Case C	20	42	32-55

The following sections present the demographic data for the participants in each of the cases.

#### **4.2.1 Case A - Interview participants' characteristics**

The programme participants in Case A consisted of people living with T2DM in the programme receiver group and of HCPs and peer educators in the deliverer group.

##### **4.2.1.1 People living with type 2 diabetes**

A total of 10 people living with T2DM participated in the interviews: five men and five women. Four interview participants were recruited from courses that were currently running and who also partook in the case observations, and six interview participants were recruited from former courses that had taken place within the previous 2 years. The participants' characteristics are presented in Table 4-3.

The participants' ages ranged from 50 to 81 years (mean 65.8 years, SD  $\pm$  9.1). The men were slightly younger (mean 63.6 years, SD  $\pm$  8.7) than the women (mean 68.0 years, SD  $\pm$  9.0).

On average, participants had lived with T2DM for almost nine years before they participated in the programme; the length of time since they were diagnosed with T2DM ranged from 1 to 20 years (median length 8.5 years, IQR 6.3–15.8 years).

Most participants lived with multiple chronic conditions ( $n = 8$ ), and six participants had co-morbidities commonly related to T2DM (hypertension, dyslipidaemia, obesity and cardiovascular diseases) or reported late complications related to insufficiently controlled diabetes mellitus, such as glaucoma and neuropathy. The other two participants had co-morbidities unrelated to T2DM – for example, autoimmune disorders, arthritis or lung diseases – and the remaining two participants reported not knowing whether they had any other co-morbidity.

**Table 4-3 Demographic data of patient interviewees in Case A**

ID number	Gender	Age	Relationship status	Years since diagnosis of T2DM	Co-morbidities	Last educational qualification (equivalent to)	Profession	Employment situation
A-1-11	F	56	Married	5	Hypertension, dyslipidaemia obesity	Primary level	Housewife	n/a
A-1-16	F	60	Married	17	Ophthalmic sarcoidosis	Graduate	Contemporary dance trainer	Self-employed
A-1-14	F	70	Married	8	Glaucoma, neuropathy	Vocational training	Directress	Semi-retired
A-1-13	F	73	Married	20	n/a	Vocational training	Accountant	Retired
A-1-10	F	81	Widowed	6	Coronary heart disease	Secondary level	Secretary	Retired
A-1-18	M	50	Married	1	n/a	Postgraduate	Director	Employed
A-1-17	M	58	Married	7	Forestier's disease	Graduate	IT-network administrator	Unemployed
A-1-12	M	65	Married	19	Coronary heart disease	Vocational training	Police officer	Retired
A-1-15	M	71	Married	7	Hypertension, COPD, obesity	Graduate	Head of department	Retired
A-1-19	M	74	Single	9	Hypertension, obesity	Postgraduate	Professor/ writer	Retired

Most participants pursued further education after mandatory schooling, and eight were trained professionals or skilled labourers. Only two participants ceased their schooling after primary or secondary school because they had to work to contribute to their family income at a younger age.

The majority of participants were retired or semi-retired; six of them received pension plan benefits. This reflects the disease profile, according to which a high proportion of people living with T2DM are over 60 years old (IDF 2015). Of the remaining participants, one was employed in the educational sector, one ran a small business in contemporary dance, one was a farmhand and one was unemployed due to long-term complications resulting from chronic disease. This participant was living on disability benefits.

Most participants described some kind of social relationship within their close environment. Eight were married; one was widowed, with close ties to her family; and only one participant described few and difficult social interactions within his environment due to a disrupted, non-functioning social network. Those retired spent time with their families and grandchildren and engaged themselves in neighbourhood assistance or *pro bono* philanthropic work. One participant also had attended the programme in Case B.

#### **4.2.1.2 Healthcare professionals and peer educators**

The characteristics of the programme deliverers are summarised in Table 4-4, including both HCPs and peer educators, who jointly delivered the programme.

The courses in Case A were all delivered by females ( $n = 6$ ) with an average age of 50.7 years ( $SD \pm 3.3$ ). The experienced HCPs had a mean working experience duration of 29 years ( $SD \pm 3.7$ ). The peer educators had lived with a chronic disease for 33 years on average ( $SD \pm 6.2$ ); they had all been diagnosed with T1DM.

On average, the course deliverers had 5 years of experience in therapeutic patient education (TPE), with a longer duration for HCPs (mean 6.3 years, SD  $\pm$  2.5) than peer educators (mean 2.7 years, SD  $\pm$  1.9). Two HCPs were diabetes specialist nurses, and one was a dietician. One of the peer educators was a qualified nurse, and the two others worked in an office, one as a secretary and one as an accountant.

Two HCPs had completed the certified advanced training programme in TPE. The third had attained her qualification through regular participation in continuous training courses to fulfil the requirements for professional accreditation through the Swiss Nursing Association and the Swiss Diabetes Association (Schweizerische Diabetesgesellschaft 2014). This involved participating in at least three certified training days per year, with a focus on biopsychosocial, didactic or educational aspects, as well as partaking in a structured peer review process.

The peer educators had many years of lived experience with a chronic disease, although the duration for which they had been affected by such conditions was not a selection criterion for course delivery. Healthcare professionals approached the peer educators based on their understanding of disease and willingness to share their experiences with others. Both HCPs and peer educators participated in the programme training course prior to the delivery of the programme.

**Table 4-4 Demographic data of healthcare professional interviewees in Case A**

ID number	Gender	Age	Profession	Function in programme	Professional experience / experience of living with chronic disease (years)	Type of training in TPE	Experience of TPE (years)
A-2-14	F	48	Dietician	Facilitator	25	Certified advanced training in TPE	3
A-2-15	F	50	Diabetes specialist nurse	Facilitator	28	Continuous training TPE	7
A-2-10	F	55	Diabetes specialist nurse	Facilitator	34	Certified advanced training in TPE	9
A-2-12	F	46	Secretary	Peer educator as facilitator	35	Programme training	4
A-2-11	F	50	Accountant	Peer educator as facilitator	25	Programme training	4
A-2-13	F	55	Nurse	Peer educator as facilitator	40	Programme training	< 1



## **4.2.2 Case B – Interview participants' characteristics**

The interview participants in Case B included people with T2DM and cardiovascular risk factors as programme receivers and HCPs from multiple disciplines as programme deliverers.

### **4.2.2.1 People with type 2 diabetes and cardiovascular risk factors**

The sample consisted of programme participants in two group settings who were interviewed at the end of the courses or, at the latest, two months after finishing the programme. The sample contained eight men and two women. The participants' ages ranged from 45 to 74 years (mean 59.4 years, SD  $\pm$  9.9). The characteristics are illustrated in Table 4-5. In addition to being diagnosed with T2DM, the participants had additional cardiovascular risk factors: Five were overweight, three mentioned high blood pressure, two had coronary heart diseases and one had a high level of low-density cholesterol. Two also mentioned being affected by arthritis or neuropathy. The length of time since the participants had been diagnosed with T2DM ranged from 1 to 10 years (median 4.5 years, IQR 2.1–8.0 years). This included one participant who had been directly diagnosed with both T2DM and coronary heart disease only a year before. However, most participants had lived with the diagnosed condition for almost 5 years before participating in this programme.

All interviewees participated in the case observation groups (see Table 4-10, p.140). In one group, the course participants were exclusively male professionals who had been educated to a graduate or postgraduate level and who had diverse professional and personal backgrounds. Two of these five were employed in higher-level positions in the engineering or pastoral care sectors, one was semi-retired but continued working in his own company and one was retired and writing books. The unemployed participant had been off work since going through a professional and personal crisis that had resulted in mental exhaustion and depression.

**Table 4-5 Demographic data of patient interviewees in Case B**

ID number	Gender	Age	Relationship status	Years since diagnosis of T2DM	Co-morbidities	Last educational qualification (equivalent to)	Profession	Employment situation
B-1-12	F	45	Divorced	2	Dyslipidaemia	Vocational training	Hairdresser	Self-employed
B-1-15	F	57	Married	1	Obesity	Secondary level	Nursery aide	Unemployed
B-1-16	M	47	Divorced	5	Neuropathy, obesity	Secondary level	Driver	Unemployed
B-1-19	M	50	Married	8	Hypertension	Graduate	Engineer	Employed
B-1-17	M	56	Married	4	Arthritis, obesity	Graduate	Pastor	Employed
B-1-11	M	60	Divorced	4	Hypertension	Vocational training	Technician	Unemployed
B-1-18	M	62	Divorced	10	Coronary heart disease	Graduate	Computer specialist	Unemployed
B-1-13	M	70	Married	8	Obesity	Vocational training	Printer	Retired
B-1-14	M	73	Married	1	Coronary heart disease	Graduate	Engineer	Semi-retired
B-1-10	M	74	Single	9	Hypertension, obesity	Postgraduate	Professor/ writer	Retired

The other group consisted of four skilled labourers and an unskilled worker (see Table 4-10, p.140). All of them had finished at least secondary education, and three had continued with vocational training. In that group, two of the three unemployed participants reported that the reasons for their unemployment were related to disease and late complications. For instance, the 47-year-old professional driver had to relinquish his work due to severe neuropathy. Most interview participants were embedded in a social environment. Half of the participants were married, and the others were either living with someone or described another form of social relationship with families or friends. Two participants mentioned difficult social interactions within their environment.

#### **4.2.2.2 Multi-professional healthcare team**

The sample of HCPs included interdisciplinary team members involved in the programme delivery. Ten programme deliverers were interviewed: three men and seven women with an average age of 42 years ( $SD \pm 10.1$ ) – with slightly younger ages among the women (mean 40.0 years,  $SD \pm 11.1$ ) than the men (mean 42.7 years,  $SD \pm 4.9$ ).

This sample consisted of two diabetologists, one physiotherapist, one sports therapist, two dieticians, three diabetes specialist nurses and one psychologist. Their average work experience was 12 years (median length 12.5 years, IQR 5.5–19.5 years), and their average experience with TPE was almost 6 years (median length 5.5 years, IQR 2–13 years). The HCPs were involved in the programme delivery by monitoring physical activities, examining participants' health status or giving workshops – or a combination of these programme components. Four of the HCPs were trained in motivational interviewing, one participated in the awareness training in Case C, and another followed the programme training. Four HCPs participated in continuing training programmes for therapeutic education in diabetes education. The demographic data are presented in Table 4-6.

**Table 4-6 Demographic data of healthcare professional interviewees in Case B**

ID number	Gender	Age	Profession	Function	Professional experience (years)	Training in TPE	Experience with TPE (years)
B-2-14	F	29	Diabetes specialist nurse	Nurse clinician	4	Continuing training in TPE	2
B-2-18	F	29	Dietician	Dietician	5	Training motivational interviewing	2
B-2-19	F	30	Physiotherapist	Clinical physiotherapist	5	TE-AW training	1
B-2-12	F	35	Psychologist	Clinical psychologist	7	Training motivational interviewing	6
B-2-15	F	47	Dietician	Dietician	20	Continuing training in TPE	10
B-2-11	F	54	Diabetes specialist nurse	TPE, podology	34	Continuing training in TPE	24
B-2-13	F	56	Diabetes specialist nurse	TPE	33	Training motivational interviewing	25
B-2-10	M	37	Sports therapist / educator, coach	Course monitor	10	Programme training	1
B-2-16	M	42	Diabetologist	Diabetologist	15	Training motivational interviewing	5
B-2-17	M	49	Diabetologist	Head of department	18	Continuing training in TPE	14

### **4.2.3 Case C – Interview participants' characteristics**

The interview participants of Case C consisted of HCPs (with different specialisations) who participated in the awareness-raising programme as programme receivers and HCPs who were trained in TPE as programme deliverers.

#### **4.2.3.1 Healthcare professionals participating in awareness training**

This sample consisted of 12 HCPs participating in one of the awareness-raising programmes on therapeutic education. Nine participants were recruited from current courses, and three had completed the course (within the previous two years). The current course participants were interviewed within two months of the course ending. One participant was involved in the programme delivery of Case B. The interview participants' characteristics are presented in Table 4-7.

The majority ( $n = 6$ ) of participants were nurses; two were physiotherapists; and the remaining participants were a dietician, a podiatrist and a medical and pharmaceutical assistant. Eleven were women, and one was a man, with ages ranging from 23 to 56 years (mean 40.6 years,  $SD \pm 12.4$ ). Participants in assistance positions were considerably younger; their average age was under 25 years (mean 24.5 years,  $SD \pm 1.5$ ), while the certified HCPs were on average almost 44 years old (mean 43.8 years,  $SD \pm 11.1$ ). The duration of average work experience was over 17 years (median 17.5 years, IQR 5–25 years).

When the course was delivered, no general practitioners or other medical specialists were participating in the programme. The assistants had registered in the programme at the request of their superiors, one of whom was a general practitioner and the other a pharmacist. One group participated in the courses at a community centre in a medium-sized town in a rural area. The other met either in a community healthcare centre or private hospital.

**Table 4-7 Demographic data of programme receiver interviewees in Case C**

ID number	Gender	Age	Profession	Function	Professional experience (years)	Training in TPE	Experience with TPE (years)
C-1-14	F	25	Nurse	District nurse	5	TE-AW	< 1
C-1-20	F	30	Physiotherapist	Clinical physiotherapist	5	TE-AW	< 1
C-1-16	F	33	Dietician	Clinical dietician	6	TE-AW	1
C-1-15	F	40	Nurse	Rehabilitation care nurse	19	TE-AW	< 1
C-1-18	F	41	Podiatrist	Clinical podiatrist	21	TE-AW	1
C-1-17	F	48	Nurse	Nurse educator researcher	25	TE-AW	< 1
C-1-12	F	54	Physiotherapist	Independent physiotherapist	26	TE-AW	< 1
C-1-22	F	55	Nurse	District nurse team leader	40	TE-AW	< 1
C-1-10	F	56	Nurse	Independent nurse practitioner	25	TE-AW	< 1
C-1-19	M	56	Nurse	Clinical nurse specialist	16	TE-AW	2
C-1-11	F	23	Medical assistant	Coordination in medical office	2	TE-AW	< 1
C-1-13	F	26	Pharmaceutical assistant	Basic patient advice in pharmacy	5	TE-AW	< 1

#### **4.2.3.2 Healthcare professionals trained in therapeutic education**

The demographic data of the HCPs certified in TPE are presented in Table 4-8. Eight programme deliverers were interviewed: three men and five women, with an average age of 52.2 years (SD  $\pm$  6.2). The men were slightly younger (mean 49.7 years, SD  $\pm$  4.0) than the women (mean 54.2 years, SD  $\pm$  6.7).

Two participants were diabetologists, three were diabetes specialist nurses and there was one generalist, one pharmacist and one nurse with a cardio-rehabilitation background. The length of professional experience in this programme deliverer sample was on average 19 years (median 19.0 years, IQR 15.8–25 years).

Five of the eight HCPs had some kind of leadership work function, such as head of department, team leader, superior clinical position or independent specialist with their own practice. Two participants' main roles were in care coordination and transfer, and one participant's main role was as a clinical TPE leader in the department.

All of the experienced HCPs were trained in TPE, and, on average, their TPE work experience was almost 11 years (median 10.5 years, IQR 8.0–16.3 years). Five of the HCPs held a diploma in advanced studies in therapeutic patient education (DAS TPE), and three participated in continuing training programmes for TPE. Two HCPs jointly delivered the courses in teams, of whom at least one held a diploma.

**Table 4-8 Demographic data of programme deliverer interviewees in Case C**

ID number	Gender	Age	Profession	Function	Professional experience (years)	Training in TPE	Experience with TPE (years)
C-2-13	F	43	Diabetologist	Diabetologist in own practice	12	DAS TPE	11
C-2-11	F	55	Diabetes specialist nurse	Team leader	21	Continuing training TPE	10
C-2-17	F	59	Diabetes specialist nurse	Coordination and transfer	37	Continuing training TPE	9
C-2-16	F	59	Diabetes specialist nurse	Coordination and transfer	6	Continuing training TPE	5
C-2-12	F	60	Nurse	Cardiovascular rehabilitation	40	DAS TPE	15
C-2-10	M	44	Pharmacist	Head of department	20	DAS TPE	4
C-2-15	M	52	Generalist	General practitioner	20	DAS TPE	17
C-2-14	M	53	Diabetologist	Clinical diabetologist	30	DAS TPE	18



### **4.3 Description of samples in case observations**

This section describes the participants in the course observations and presents the context in which the programmes were delivered. In total, 88 hours of observation were completed, during which field notes were taken. All observations were undertaken with the full knowledge of group participants. The characteristics of the HCPs delivering the programme are presented above. The characteristics of the participants who received the programme are presented according to the group settings.

#### **4.3.1 Case A – Observational sample characteristics**

The sample observed in Case A consisted of people living with different chronic conditions.

##### **4.3.1.1 Participants with different chronic conditions**

In this case, a total of 24 hours of observations were conducted of two groups in different settings: complete course participation in setting A-1 (15 hours) and observations on separate occasions in setting A-2 (9 hours). In total, 15 participants were observed in the sessions. Almost half of them were living with multiple chronic conditions ( $n = 7$ ), which was to some extent comparable with the interviewees in Case A. Four of the participants with T2DM were recruited for in-depth interviews. The range of chronic conditions represented in these courses was broad and consisted of people living with the following: endocrine and metabolic disorders ( $n = 8$ ), cardiovascular diseases ( $n = 3$ ), neurological conditions ( $n = 3$ ), autoimmune disorders ( $n = 1$ ), rheumatic illnesses ( $n = 3$ ), lung diseases ( $n = 1$ ) and mental health disorders ( $n = 4$ ). The demographic data of participants in the observed courses are presented in Table 4-9.

**Table 4-9 Demographic data of observational samples in Case A**

Gender	Age	Marital status	Chronic conditions	Last educational qualification (equivalent to)	Profession	Employment situation
<b>Setting group A-1</b>						
F	46	Divorced	Multiple sclerosis, depression	Graduate	Social worker	Unemployed
F	49	Single	Depression	General certificate of education advanced level	Secretary	Unemployed
F	55	Married	T1DM	Graduate	Nurse	Employed
F	60	Married	T2DM, ophthalmic sarcoidosis	Graduate	Contemporary dance trainer	Self-employed
F	65	Divorced	Hypertension, hypothyroidism, obesity, cancer	Vocational training	Operating room nurse	Retired
F	72	Divorced	Vascular disease, hypertension stroke survivor	Primary	Domestic worker	Retired
F	73	Divorced	Rheumatoid arthritis, depression	Graduate	Teacher	Retired
F	73	Widowed	Osteoarthritis	Vocational training	Secretary	Retired
M	71	Married	T2DM, hypertension, COPD, obesity	Graduate	Head of department	Retired
<b>Setting group A-2</b>						
F	34	Married	T1DM	General certificate of education advanced level	Event organiser	Self-employed
F	38	Married	T1DM	Vocational training	Laboratory assistant	Employed
F	40	Married	Multiple sclerosis	Vocational training	Adult coach	Employed
F	70	Married	Parkinson's disease	Vocational training	Accountant	Retired
M	50	Married	T2DM	Postgraduate	Director	Employed
M	58	Married	T2DM, Forestier's disease	Graduate	IT network administrator	Unemployed

Of the total of 15 participants, the majority were female ( $n = 12$ ). The participants' ages ranged from 34 to 73 years (mean 56.9 years,  $SD \pm 13.1$ ), with considerably younger ages in setting A-2 (mean 48.3 years,  $SD \pm 12.6$ ) than setting A-1 (mean 62.7 years,  $SD \pm 8.6$ ). Most participants had finished at least secondary-level education, and some had continued with vocational training ( $n = 4$ ) or at the tertiary level with graduate or postgraduate education ( $n = 7$ ). One participant, who was in her seventies, had only attended primary school.

The majority of participants were educated professionals and were either employed ( $n = 4$ ), self-employed ( $n = 2$ ), retired ( $n = 5$ ) or unemployed ( $n = 3$ ). Unemployment was mostly due to long-term complications related to chronic disease, and unemployed individuals were either living on unemployment or disability benefits at the time of the study. Those who were self-employed ran small businesses in the arts or services sector. Employed participants worked in either healthcare or education. The retired individuals described their time as filled with activities related to family, community, neighbourhood assistance, writing or other hobbies. In setting A-2, all participants were married in contrast to setting A-1, where most participants were either single, divorced or widowed.

#### **4.3.1.2 Group settings for the peer exchanges**

Either a diabetes specialist nurse or a dietician jointly delivered the programme with a peer educator. The programme facilitators provided the courses in different locations. Setting group A-1 was in a healthcare centre, combining general and specialist services. The majority of the adult population living permanently in this area are trained professionals or skilled labourers (Statistique Vaud 2016). The course sessions were delivered after office hours in the break room of the healthcare centre on the first floor of the building, which the healthcare team normally used for short coffee breaks and at lunchtime. The room had large windows, brightening the space with daylight and offering a view of the green surroundings. The meetings took place

in the evening from 18:30 to 21:00, so the room had to be artificially lit, maintaining a warm homely atmosphere.

Setting group A-2 was in a regional hospital that was part of a hospital network. In this more urban area, over one third of the general population finishes their education with a tertiary degree (Statistique Vaud 2016). The courses were either delivered in a medium-sized meeting room or, if not available, in the canteen of the hospital (outside of its regular use). From the main entrance, participants had to descend one level to the garden floor. After the courses, participants had to leave through the emergency department because all other exits were closed after official hospital visiting hours. In contrast to the warm atmosphere in setting A-1, these sessions were conducted in a clean and sterile hospital setting with the slight smell of the disinfectants typically used in clinics. In addition, group facilitators had to ensure all participants could access the rooms, which was only possible through sliding doors with an access key.

#### **4.3.2 Case B – Observational sample characteristics**

This sample consisted of people living with T2DM and cardiovascular risk factors who participated in all observed course sessions. As these individuals also participated in the interviews, the sample is identical with the patient interview participants in Case B.

##### **4.3.2.1 People living with type 2 diabetes and cardiovascular risk factors**

The demographic data, according to setting, are presented in Table 4-10. Eight men and two women were observed, with younger ages in setting B-1 (mean 55.8 years, SD  $\pm$  9.1) than in setting B-2 (mean 63.0 years, SD  $\pm$  9.4). A total of 40 hours of observations were conducted: 10 hours in setting B-1 and 30 hours in B-2.

**Table 4-10 Demographic data of observational samples in Case B**

Gender	Age	Marital status	Chronic conditions	Last educational qualification (equivalent to)	Profession	Employment situation
<b>Setting group B-1:</b>						
F	45	Divorced	T2DM	Vocational training	Hair dresser	Self-employed
F	57	Married	T2DM	Secondary level	Nursery aid	Unemployed
M	47	Divorced	T2DM, neuropathy	Secondary level	Driver	Unemployed
M	60	Divorced	T2DM, hypertension	Vocational training	Technician	Unemployed
M	70	Married	T2DM	Vocational training	Printer	Retired
<b>Setting group B-2:</b>						
M	50	Married	T2DM, hypertension	Graduate	Engineer	Employed
M	56	Married	T2DM, arthrosis	Graduate	Pastor	Employed
M	62	Divorced	T2DM, coronary heart disease	Graduate	Computer specialist	Unemployed
M	73	Married	T2DM, coronary heart disease	Graduate	Engineer	Semi-retired
M	74	Single	T2DM, hypertension, obesity	Postgraduate	Professor/writer	Retired

#### **4.3.2.2 Group settings for the physical activity and workshop classes**

The setting of group B-1 was part of an inter-cantonal hospital network serving a population in a rural, mostly agricultural area. Almost four of five people in this area finish their schooling after the secondary level or with professional training, and a high proportion of people work in the agricultural and industrial sectors (Federal Statistical Office 2015, Statistique Vaud 2016). The courses were delivered by physiotherapists who were also involved in the metabolic centre established in the hospital network. On average, the centre offers 18 different fitness classes per week. This programme took place from 08:00 to 09:00 and combined different physical activities, such as Aquagym, machine training, gymnastic sessions and Nordic walking. The training was delivered over three weekly lessons. After the training sessions, different HCPs jointly led a series of six workshops that followed themes related to nutrition, physical activity and disease treatments. In addition, the physiotherapists organised regular social gatherings to encourage current and previous participants to continue their training together in a supportive and friendly environment.

The setting of group B-2 was an urban location serving a more cosmopolitan population. About 40% of people living in this area have a degree or postgraduate education (Statistique Vaud 2016). The programme was conducted in a physiotherapy centre, which was part of a private medical network located near the lakeside and in proximity to universities and multinational companies. The one-hour indoor training took place twice weekly and started at 17:15; four-times followed by a two-hours workshop. The outdoor sessions with Nordic walking were organised during lunchbreak from 12:15 to 13:15 once a week. The training trail ran along a lake next to a sports stadium and led to a public park with walks. The nearby training grounds were also used by professional athletes to prepare for competition. Thus, there were always people in the area walking, running or doing other sporting activities, creating a sporty and dynamic atmosphere.

### **4.3.3 Case C – Observational sample characteristics**

The sample observed in Case C contained HCPs from various disciplines and professional backgrounds with an interest in therapeutic education.

#### **4.3.3.1 Healthcare professionals with interest in therapeutic education**

This sample consisted of 12 HCPs from different disciplines who participated in two settings of the TE-AW programme. In total, 24 hours of observations were conducted in both settings, including 12 hours of complete participation in each setting. The demographic data are presented in Table 4-11.

Participants' ages ranged from 23 to 56 years (mean 38.8 years, SD  $\pm$  12.2), with slightly younger participants in setting C-1 (mean 37.0 years, SD  $\pm$  13.22) than setting C-2 (mean 41.2 years, SD  $\pm$  10.1). The seven participants in setting C-1 came from different professional backgrounds: Two were physiotherapists, one of whom was involved in delivering the programme of Case B; one was a nurse working as an independent nurse practitioner and specialist in lymphatic drainage; one was a pharmacist working in her own pharmacy; one was a dietician working in different primary care settings; one was a medical assistant coordinating patient care in general practice; and one was a pharmaceutical assistant who gave basic advice to pharmacy clients with chronic conditions. In setting C-2, all participants were nurses with different specialisations: Two were district nurses, one specialised in wound care, one specialised in rehabilitation care and one worked as a nurse educator and researcher.

On average, participants' work experience was almost 12 years (median length 11.7 years, IQR 4.0–25.0 years), and their experience with TPE was under 1 year. All participants voluntarily subscribed to the courses, except the two in assistant positions, who were registered at the request of their superiors.

**Table 4-11 Demographic data of observational sample in Case C**

Gender	Age	Profession	Function	Professional experience (years)	Training TPE	Experience with TPE (years)
<b>Setting group C-1:</b>						
F	23	Medical assistant	Patient coordination in medical office	2	TE-AW	< 1
F	25	Dietician	Dietician in primary care	2	TE-AW	< 1
F	26	Pharmacy assistant	Basic patient advice in pharmacy	5	TE-AW	< 1
F	30	Physiotherapist	Clinical physiotherapist	5	TE-AW	< 1
F	45	Pharmacist	Self-employed pharmacist	21	TE-AW	< 1
F	54	Physiotherapist	Self-employed physiotherapist	26	TE-AW	< 1
F	56	Nurse	Self-employed nurse practitioner	25	TE-AW	< 1
<b>Setting group C-2:</b>						
F	25	Nurse	District nurse	5	TE-AW	< 1
F	38	Nurse	Wound care nurse	12	TE-AW	< 1
F	40	Nurse	Rehabilitation care nurse	19	TE-AW	< 1
F	48	Nurse	Nurse educator, researcher	25	TE-AW	< 1
F	55	Nurse	District nurse, team leader	40	TE-AW	< 1



#### **4.3.3.2 Group settings for the awareness-raising programme**

The programme is jointly delivered in both settings by at least two HCPs from different disciplines who are certified and experienced in TPE. At the time of this study, the HCPs were two diabetologists, two nurses and one pharmacist.

Setting group C-1 was in a technology park located on the outskirts of a larger industrial city in the north of the canton, which is easily reachable and close to motorways. The participants were serving a population with a high proportion of people with minimal schooling; in that area most people are trained as skilled labour (Statistique Vaud 2016). The group participants worked in different communities in the north and north-east regions of the canton. The regional health network rented the meeting room, which was in an office building, for local course delivery. The meeting room was functionally furnished with rectangular tables and office chairs. As is typical in meeting rooms, there were no pictures on the walls. An elongated window let daylight in. For coffee breaks, participants went to the restaurant next door, where coffee, tea, fruits and fruit cakes were offered. This short walk nicely broke up the rather official functionality of the environment.

Setting group C-2 was in the offices of the regional health network, which served the population in the south-western area of the canton. In this area, almost half of people over the age of 30 have a degree or postgraduate education (Statistique Vaud 2016). Participants in this group setting were exclusively nurses with different specialisations. As in setting C-1, the tables and chairs were placed in a U-shape with sufficient space in the middle to work with flipcharts and perform role plays. The course sessions took place on three afternoons for 4 hours, from 13:30 until 17:30. The last meeting took place in a separate building in a private hospital located within a park near the lakeside with beautiful views of the French alps.

#### **4.4 Description of documentary data**

This section presents the type and content of documents collected in the study and describes how written and visual information communicated the programme content related to the integration of self-management education within the context. The following documents were considered: programme leaflets and handouts, programme books and curricula (where available), information on websites related to the cases and cantonal guidelines and recommendations. The programme images of the cases are described in vignettes and are not reproduced for copyright reasons.

##### **4.4.1 Case A – Documents in exchange programme**

In Case A, documentary data from the following sources were examined: the programme information leaflet, the translated and culturally adapted programme book (Lorig *et al.* 2012) and two programme websites (DiabèteVaud 2016, EVIVO Réseau 2016).

These sources all used promising slogans that captured the ethos of the programme, such as the following excerpt from the programme leaflet:

EVIVO – becoming the actor of your own health with chronic disease ...

The courses allow to develop and test practical tools on how to handle daily challenges in living with chronic disease.

*(EVIVO – devenir acteur de sa santé avec une maladie chronique ...*

*Les cours permettent de développer et expérimenter des outils pratiques pour gérer le quotidien et les questions relatives au comment vivre avec une maladie chronique.)*

The programme documents used an image to represent the programme's purpose of empowering and supporting people to live healthy and actively with their disease. The image depicts a relaxed atmosphere, illustrated by two people of different ages leaning on each other. This may symbolise the social support created in the EVIVO groups, where people may exchange their many different perspectives and lived

experiences with chronic conditions. Because this is a process, the courses may support people living with chronic disease in the developments of self-management activities. The supportive and relaxed spirit of the programme is captured in the image described in Vignette 4-1.

<p><b>Vignette 4-1 Description of programme image (EVIVO Réseau 2015)</b></p>
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<p>On a late summer day, a man who is probably in his sixties is with a girl, maybe his granddaughter, who is about seven years old. They are sitting back-to-back on a hay bale in a mowed field. Both look up to the blue sky, which is covered with light cumulus clouds that look like soft cotton balls. The girl wears a flowered pink dress and sandals; sunglasses protect her eyes. The man is wearing relaxed clothes with a black jacket, beige trousers and brown shoes without socks. He has grey-mottled full hair. His arms are loosely wrapped around his knees.</p>
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#### 4.4.2 Case B – Documents in physical activity programme

In Case B, two programme leaflets (including the course content and description) and two websites were considered (DIAfit 2016, Réseau Santé Nord Broye 2016). The programme was advertised through different means, such as radio broadcasts, to raise public awareness of the health benefits of physical activity. The message was to invite people with T2DM to this group education programme, as expressed in the leaflet with the slogan:

Welcome to DIAfit – for people with diabetes

*(Bienvenu chez DIAfit - pour les personnes diabétiques)*

As suggested with the image on the programme welcome page (DIAfit 2016), the courses encouraged people with T2DM and cardiovascular risk factors to be physically active within a healthy environment safely supervised by a trained group facilitator. The image may suggest that activity can be for everyone at any stage, and the fact that people train together may emphasise the social nature of the programme as well as the support individuals may get from participation. One of the women

depicted in the image is smiling, which may suggest that the physical activities performed in the training groups are pleasurable rather than arduous, thus encouraging people to feel they can be active in a safe environment with professional support. The healthy and supportive environment is captured in the programme image described in Vignette 4-2.

<p><b>Vignette 4-2 Description of programme image (DIAfit 2016)</b></p>
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<p>On a sunny day, a group of people is walking outdoors. The surrounding area is rather flat, just slightly hilly. On the horizon, bushes and trees can be seen. They wear comfortable clothes – tee-shirts and relaxed trousers. They all use Nordic walking sticks for training. Two of the group members can be identified as women, and a further person is hidden behind the group. The man is most likely the group facilitator. The women are likely to be in their second half of life. One of the overweight women is smiling.</p>
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#### 4.4.3 Case C – Documents in awareness-raising programme

In Case C, documentary data from the following sources were considered: programme leaflet, handout, description (including programme content) and the website containing programme information (Programme cantonal Diabète 2016b). The programme addresses HCPs, seeking to raise their awareness of therapeutic education (Sofra *et al.* 2014). As promoted in the programme documentations and the website, the programme focuses on the whole interdisciplinary team in order to introduce them to the field of therapeutic education and to enhance their capabilities to care for people living with chronic diseases:

The support of people living with chronic disease may be challenging for many caregivers.<sup>3</sup> You can reinforce your capabilities and become familiar with new tools by participating in the course: Awareness on therapeutic education.

*(La prise en charge des patients atteints de maladie chroniques est un défi pour les soignants. Renforcez vos compétences en utilisant de nouveaux outils et participez au cours de: Sensibilisation à l'éducation thérapeutique.)*

The programme is offered in all four health networks within the canton of Vaud (DiabèteVaud 2018). Collaboration between the four regional health networks is represented in an image that depicts the networks in different colours. In relation to the TE-AW courses, the image may symbolise the intention of PcD to support collaborations between HCPs to enhance, develop and implement shared understandings of care for people in their network. The collaborative spirit to raise awareness regarding therapeutic education is captured in the image on the programme leaflet, which is described in Vignette 4-3.

#### **Vignette 4-3 Description of programme image (DiabèteVaud 2015)**

Two logos are presented on the leaflet, in addition to the cantonal emblem. One logo consists of four puzzle pieces within a circle that is open to the right side and filled with the name of the cantonal diabetes programme. All puzzle pieces are coloured in different shades of green. Three of the pieces are connected, and one is slightly apart within the circle. The other logo consists of two interconnected graphs. On the left, the graph is transparent and overlapped with the lettering of the health network's name. On the right side, the figure is subdivided into four areas, each painted in a different colour: purple, dark blue, light blue and green. The five-pointed forms are interconnected and compose a rounded form representing a circle. The programme name is surrounded by a fine-lined circle.

<sup>3</sup> The term "caregivers" (*les soignants*) is used in TPE to describe all healthcare professionals involved in the process of caring for people living with chronic disease.

#### **4.4.4 Cantonal recommendations and guidelines**

In addition to the documents of the cases, cantonal guidelines and recommendations were considered. The cantonal recommendations were established according to the advice of an interdisciplinary expert group and adapted to the local context based on international evidence-based guidelines and recommendations (Programme cantonal Diabète 2017). With regard to therapeutic education, the guidelines underline the importance of education and supporting people with T2DM to enable them to engage in decision-making about their diabetes by providing them with the emotional, psychosocial and practical support they need to actively participate in their treatment plans (Programme cantonal Diabète 2015). To fulfil the quality requirements for programme delivery, the guideline emphasises that the HCPs were trained in therapeutic education and that they engage in practice and regular follow-up in the form of continuous education (Programme cantonal Diabète 2015).

The recognition of the importance of therapeutic education in the cantonal guidelines encourages HCPs to engage with this care, as it suggests that therapeutic education is a normative aspect of care delivery integrated into the cantonal context. Such guidelines and recommendations may help regulate and standardise delivery and may support HCPs in participating in and implementing caregiving so as to stay current with peers with regard to care approaches.

#### **4.5 Inter-case interpretation of descriptions**

In this section, the participants' characteristics are considered across the cases as a whole to form a perspective of the similarities and differences between them. This comparison may contribute to a deeper understanding of the contexts of integration.

A commonality shared by the programme receivers in cases A and B was that many were living with multiple chronic diseases. Most were affected by at least one

additional medical disorder in addition to having T2DM. In these cases, the combined average age of the patient interview participants was nearly 63 years old. Participants of observed group setting A-2 had the youngest mean age of slightly more than 48 years and fewer co-morbidities. This relates to previous research showing that the prevalence of co-morbidities increases with age and influences the use of healthcare services (Barnett *et al.* 2012, Palladino *et al.* 2016).

Delayed programme attendance among people with diagnosed T2DM has previously been highlighted to cause insufficient self-management support (Winkley *et al.* 2016, Horigan *et al.* 2017). In the present study samples, the primary reason for such delay was that participants were able to access other sources of help, such as e-learning courses, patient conferences and face-to-face support at their point of care.

More women were present at the observational data collection sessions of the courses in Case A. This is consistent with other studies. For example, a meta-analysis of 23 studies with 8688 participants from predominately white populations reported that 75% of participants were female (Brady *et al.* 2013). The female preponderance was also noted in the evaluation of the initial implementation of EVIVO, where almost 90% of participants were women (Haslbeck *et al.* 2015). Conversely, in the Case B samples, more men than women participated; indeed, in one setting, all participants were male. These observations differ from the study sample of a cross-sectional study in a similar context that shows a relationship between physical fitness and educational level, but where a male preponderance was not noted (Allet *et al.* 2016). Nonetheless, programme participation may also vary by gender and their social perceptions in addition to educational level and individual preferences.

The majority of participants in both cases either had skilled labour training or were professionals with graduate degrees, although three of the four settings also included participants who finished their education after mandatory schooling. Nevertheless, the present study samples with self-reported data had a slightly higher educational level

compared to the average population of the canton of Vaud, where around 27% of people leave training after mandatory schooling (Statistique Vaud 2016). Overall, the samples were similar to the populations living in these areas. Two of the settings were in regions where 70% to 80% of people had mandatory schooling and vocational training; the other settings were in districts with a higher proportion of people with graduate training (Statistique Vaud 2016).

In both cases, participants with different educational backgrounds mentioned unemployment as a relevant factor in their experiences with T2DM. This was reported in all settings except one in which most participants were retired. The issue of unemployment was raised most frequently in the group with more unskilled workers. Both the graduate professionals and the labourers reported losing their jobs following either a restructuring at their workplaces or a longer period of sick leave. Four of five unemployed participants reported limited possibilities for new job applications due to their health status. The negative impact that diabetes might have on employability, such as increased risks for disability and early retirement, has been previously described (Herquelot *et al.* 2011, Breton *et al.* 2013). In the present study samples, co-morbidities were highly prevalent, and 20% of participants were affected by some disability-related work impairment. In both cases, some participants reported that their loss of regular work influenced their social network, although the majority described some kind of social support – mostly from their spouses, families, friends or neighbourhood support groups.

The characteristics of the course deliverers who participated in the case interviews varied, but the HCPs were all trained in self-management education. In Case A, the deliverer sample consisted of HCPs and peer educators who shared the common aim of developing and reinforcing self-management strategies in people living with different chronic diseases. All the programme deliverers were women, mirroring the receiver group, which was also mostly female. Both HCPs and peer educators were



experienced in either professionally supporting people living with chronic disease or in personally dealing with such diseases.

In Case B, the sample contained members of the interdisciplinary healthcare team from different professional backgrounds, all of whom contributed to the programme delivery by supporting the course participants in increasing their physical activity levels and understanding of their disease. Similarly to the other cases, these HCPs had many years of professional experience, some in leadership functions. Almost half were also trained in applying different techniques often used in TPE, such as motivational interviewing. Some HCPs also participated in the specific programme training, in the TE-AW programme and compulsory continuous training days.

In Case C, both deliverer and receiver groups were comprised of HCPs. Beyond different professional experiences, they shared an interest in TPE, and, in every course, at least one of the programme deliverers had advanced TPE training. Similar in all cases, the HCPs were trained and had experience in the programme delivery.

## **4.6 Summary**

In the preceding chapter, the data samples collected from the four different data sources are described. The interview participant characteristics of both patients and HCPs in the three cases are detailed, as well as the samples of participants that were directly observed. In addition, the contexts are described in which the programmes were delivered, and the documents analysed are outlined. The chapter concludes with an inter-case interpretation of the data descriptions.

The following chapters present the individual case reports – the findings from Case A in Chapter 5, Case B in Chapter 6 and Case C in Chapter 7. These findings are synthesised in order to understand integration in relation to self-management education in routine care, as presented in Chapter 8.

## **Chapter 5 Case A – Developing capabilities to self-manage everyday activities**

This chapter begins by setting the scene for the programme in Case A and presents the findings within that context. The findings relate to the programme features that convey the nature of integration at the individual and interpersonal levels and either encourage or impede the development of self-management behaviour and the delivery of education and support, respectively. The data are organised thematically into three main themes with nine sub-themes. Each theme, with its sub-themes, is presented separately and validated with data excerpts from different data sources to show cross-connectivity.

An overview of the identified themes and sub-themes is presented in Table 5-1.

**Table 5-1 Themes and sub-themes in Case A**

<b>Themes</b>	<b>Sub-themes</b>
1) The nature of integration in Case A	<ul style="list-style-type: none"><li>• Sharing symptoms of chronic disease</li><li>• Finding meaning in experience</li><li>• Valuing experiential and professional expertise</li></ul>
2) The development of self-management behaviour	<ul style="list-style-type: none"><li>• Using tools in self-management support</li><li>• Recognising individual expectations</li><li>• Continuing with extended resources</li></ul>
3) The divergent interests in self-management	<ul style="list-style-type: none"><li>• Varying group dynamics</li><li>• Spreading the news</li><li>• Incorporating context</li></ul>

## 5.1 Setting the scene for the programme in Case A

In this programme, the course deliverers acted as facilitators rather than as formal educators. At the beginning of each of the observed courses, the facilitators gave a short overview of the programme structure, its content, the processes that would be used to encourage group discussions and their roles as programme facilitators. Most sessions were similar in nature and were organised with the participants at the centre of a shared learning experience, in which they were encouraged to voice their personal experiences. The facilitators enabled this by creating an open and participative learning environment. Vignette 5-1 provides a synopsis of a typical group session.

### Vignette 5-1 Synopsis of typical group sessions in Case A

Both facilitators welcomed the participants using their names when the participants entered the room. The facilitators were either standing beside the door or doing final course preparations such as pinning up posters or arranging chairs and tables so that everybody could easily see and talk to each other.

“We want you to feel comfortable in the courses”, one of the facilitators said. The other explained that this programme supports participants in putting into practice what they knew they should do but cannot for “a thousand and one reasons”. They highlighted that this programme gives the participants the opportunity to share their experiences and practices so they could explore them together to seek ways of improving their health and well-being. The facilitators’ role was to support the exchange of participants’ experiences, and they shared thoughts on how people might identify personal goals. Metaphorically, this was expressed as a “journey” to recognise that the participants were “on a wider path with turns”.

The facilitators used figurative language in the sessions and adapted expressions to the scheduled theme. One of the final phrases communicated by the facilitators in the introductory session was: “We like to be here with you and we always learn from you as much as you learn from us”. This sentence indicated that the facilitators were positioning themselves alongside the participants to help guide them and that this was a shared experience. Similar expressions were used in all of the course sessions.

(Field notes, participant observations A-1, A-2)

During the sessions, the facilitators used visual prompts to direct and encourage discussion and to affirm understanding. The facilitators pinned up poster boards to give general direction to the group for addressing the meetings' objectives. The facilitators regularly referred to the posters – to set the scene for the session, to keep the group on course and to serve as a focal point for summing up. While the programme was delivered in a flexible and responsive style, the themes discussed during the course sessions were clearly structured by the facilitators so that they followed the programme curriculum. The programme posters and documents were an integral part of conveying the programme across the different settings of programme delivery.

## **5.2 The nature of integration in Case A**

It was possible to identify different areas in which the programme seemed to help patients integrate their treatments and conditions into their everyday activities through exchanging lived experiences and recognising support. These can be represented by the following sub-themes: sharing symptoms of chronic disease (to learn from each other), finding meaning in experience (of living with their condition) and valuing experiential and professional expertise (by bringing together the professional and lay perspectives and giving equal value to both contributions). The programme featured these aspects through exchange sessions collaboratively delivered by two facilitators: an HCP and a trained person living with chronic disease in the role of peer educator. The theme and sub-themes are validated with data excerpts from the different sources (see Table 5-2).

**Table 5-2 Theme 1: The nature of integration in Case A with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme facilitator interview data	Programme participant interview data	Observational data	Documentary data
The nature of integration in Case A	Sharing symptoms of chronic disease	"We support them to share their thoughts on the chronic disease and the symptoms as it's not always easy to balance that with the rest of their life's demands ... and the emotional responses are certainly not easy to integrate." (A-2-10)	"I recognised myself in the circle of symptoms. I've always thought that was me but now recognise that it was the disease that made me tired". (A-1-16)	Participants discussed different symptoms that influence their perceptions; some reacted with surprise when recognising that they all struggle with handling symptoms despite their different life issues and representations. (Field notes, A-1, A-2)	Artefacts illustrating the circle of symptoms. (Poster board, programme book)
	Finding meaning in experience	"[We talk about] a journey through life, precisely, there are turns; it's not a straight road, it goes downhill and uphill, there are obstacles ... And living with a chronic disease is adding more ups and downs." (A-2-15)	"I think that it is important to seek precisely this experience, because it is often on this experience that we base our learning. It's the example ... someone says something and it, it speaks to me, and I put [it] in place." (A-1-19)	The facilitators often used metaphors, such as that of a journey to indicate the phases the participants undergo when living with their conditions. Some of the participants also used metaphors to describe their experience. (Field notes, A-1, A-2)	"Living with a chronic disease is a difficult process that involves enormous time, energy, effort and frequent frustration." (Programme leaflet)
	Valuing experiential and professional expertise	"I think it's very enriching, because in a way I set aside my status as a professional who knows things and tells you what to do. I really feel a lot more at the same level, which isn't an easy thing to achieve." (A-2-14)	"Sometimes it's only a matter of terminology ... They rephrased but ... they didn't just tell us what our understanding was supposed to be. I think it was their way of being included ... [in the sharing]." (A-1-17)	The facilitators frequently summarised the participants' narratives to make sure they understood the meaning expressed. They combined the different contributions and linked them with the session's theme. (Field notes A-1, A-2)	"The facilitators, both trained in this programme delivery, are a person living with a chronic disease and a healthcare professional." (Programme leaflet)

### **5.2.1 Sharing symptoms of chronic disease**

The programme participants had a range of different chronic conditions, not just diabetes. Therefore, the programme integrated conditions by focussing on common symptoms in order to identify similarities in managing and living with the disease. By underlining common symptoms, the facilitators created a shared experience with the participants, independent of their diseases.

In the sessions, the facilitators were observed to stimulate the participants' exchange of experiences by referring to "the circle of symptoms" that was illustrated on the poster board. The circle represented different symptoms, such as pain, emotions, fatigue and depression, for example, and how these may influence each other in different chronic conditions (field notes participant observations A-1, A-2). For some participants, this was surprising because they were not aware of the extent to which chronic conditions have similar symptoms that influence each other. For example, as they discussed how fatigue affected their perception of life, one of the participants observed how she identified with the symptoms when she said that "she recognised herself in the circle of symptoms" (field notes participant observations A-1). She then continued by describing how she experienced muscular pain, anxiety and exhaustion and concluded by saying that "she always thought that it was her but now recognised that it was the disease that made her tired" (field notes participant observations A-1, participant interview A-1-16). The relief was felt in her tone of voice when she talked about her disease; some others joined in the discussion and expressed similar perceptions.

By sharing their thoughts, the participants verbalised their emotions about their personal concerns. These were taken up by the facilitators, who construed the chronic disease as an additional reality to bring into balance "with the rest of their life and that

the emotional responses were not always easy to integrate” (facilitator interview A-2-10).

The examples above indicated that the participants developed their own personal understanding by talking about their experiences and sharing symptoms. These behaviours showed that participants were integrating their individual perceptions into their experiences of living with disease at both individual and interpersonal levels. The sharing of common symptoms helped participants to recognise different options for how to handle their disease based on examples of lived experiences, and it also encouraged group learning, which was prompted by the programme materials used across the settings.

### **5.2.2 Finding meaning in personal experience**

The programme addressed, from the participants’ perspectives, their experiences of living with a chronic condition such as diabetes. Participants worked together to consider the meaning of their condition and how it impacted their lives. This provided the opportunity for them to consider some of their feelings towards their condition and encouraged them to accept it more fully, thereby enabling them to accept their condition as part of their life experience rather than as a separate aspect of their being. The participants described their changing lived experiences with their disease with words and expressions that were often phrased existentially and expressed the emotional distress they felt in this ongoing process. In the example below, the process was indicated by “no longer, but now”:

I think I’m on a diabetes rally ... my frustrations, my fears, my sorrows ... all these emotions come up sometimes ... . It is no longer anger or the feeling of injustice as it was in the beginning but now I still feel frustrations.

(Participant interview A-1-13)

One of the features of this programme was that it did not consider everybody to be at a fixed point in the process of adapting to living with chronic disease. This approach meant that the programme could be flexible in incorporating different positions as it considered the participants' current state of integration independently of the time passed since diagnosis.

In the exchanges, both the participants and facilitators were observed to use the metaphor of a "journey" to indicate a process (facilitator interview A-2-15, field notes participant observations A-1, A-2). Metaphors were often voiced in the group discussions. For example, some participants downplayed their disease with humour: "Some win the lottery and some chronic diseases". Others formulated more optimistic thoughts, such as "every cloud has a silver lining" to express that they were seeing new possibilities, and others described their experience as being on an excursion with their disease as a "travel companion" (field notes participant observations A-1, A-2).

The participants' words and phrases were often expressed in a temporal context, relaying how they perceived their conditions to be changing. This enabled them to consider where they might be on their disease journey relative to others. The participants helped each other to recognise alternative options to use in their individual integration processes. Indeed, some participants based their learning on interpersonal exchange: "We learn from others who share similar life experiences" (participant interview A-1-19).

The facilitators responded to the different words and expressions used in the group, implying that they had some awareness of the phases of integration participants expressed in their dialogue. Articulating emotions in the group context emphasised that while these questions were personal to the participants themselves, they were supported by the group as illustrated in the following example: "Sharing these



thoughts helps me to understand that I'm not alone; others feel the same and make similar experiences" (participant interview A-1-15).

The verbalisation of emotions supported participants in finding meaning in the context of their disease so that they could better integrate their condition into their normal lives. Doing so is a crucial step in fully integrating self-management activities into personal care routines. Hence, the programme feature of sharing lived experience facilitated opportunities for the existential integration of meaning into a person's life and a space to share inner thoughts.

### **5.2.3 Valuing experiential and professional expertise**

Bringing together patient experiences and professional expertise in a shared process gave equal value to the contributions of both facilitators and participants in addressing the participants' expectations and needs. In the sessions, the facilitators frequently summarised the participants' narratives (field notes participant observations A-1, A-2). In so doing, they made sure they understood the meaning of those narratives and combined participants' contributions with their interpretation into a shared group experience that they linked to the discussion theme. Paraphrasing and combining the participants' experiential knowledge with their professional understanding contributed to the building of an experientially and professionally integrated learning context. The open, non-directive process of integrating the narratives of participants and facilitators into a common group experience was recognised by participants:

Sometimes it's only a matter of terminology, I think. They [the facilitators] would rephrase certain things, to make sure they understood what we were saying. They rephrased but I felt that by doing that, they were adding something. They didn't just tell us what our understanding was supposed to be. I think it was their way of being included ... [in the sharing]. They talked about their experience, even if it was only in the context of the action plan, as if they were taking part like us. The way they introduced the topics as well, not

only with questions, but also personal comments coming from them, without taking anything away from what we wanted to say ourselves. Just some added value, in a way. Sometimes they used both words – we used a word, they found another, but on the board, they would write both. And it was always a very open conversation, with a lot of respect ... it wasn't restricted.

(Participant interview A-1-17)

Exchanging experiential and professional expertise created an environment of learning for participants and facilitators in which both might benefit from reciprocal learning. The consequence of this engagement process for facilitators was that their own learning experience was self-enriching their programme practice so that they developed new insights into how to work with people living with chronic disease, therefore enhancing their understanding of person-centred self-management support. In this practice, the HCPs adopted a different role and underlined their support function in the position of partner with professional expertise, as illustrated by one of the facilitators:

I think it's very enriching, because in a way I set aside my status as a professional who knows things and tells you what to do. I really feel a lot more at the same level, which isn't an easy thing to achieve. Especially since the other facilitator is someone who also has a chronic disease. But that's what's interesting as well, I learn just as much from them, more maybe, as they learn from me on a theoretical level.

(Facilitator interview A-2-14)

This example reflected the programme ethos of integrating experiential and professional expertise to help participants consider these different perspectives in the context of their own needs.

### **5.3 The development of self-management behaviour**

This theme considers how integration observed within the programme related to participants' self-management behaviours with strategies to help them develop their self-management behaviour over time according to their expectations. The theme is comprised of three sub-themes: using tools in self-management support, recognising individual expectations, and continuing with extended resources (see Table 5-3).

**Table 5-3 Theme 2: The development of self-management behaviour with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme facilitator interview data	Programme participant interview data	Observational data	Documentary data
The development of self-management behaviour	Using tools in self-management support	"We talk about a 'toolbox'; there are many tools, and we use them to various extents during the sessions... . There are the aspects of self-management, and right, relaxation too; we have short moments to relax." (A-2-15)	"It's the first time I've felt I was being understood. I've not always learnt a whole lot [in the programme], but I did learn some things. I've always been interested to know more about my condition." (A-1-17)	The facilitators encouraged the participants to share their concrete experiences with the group. In one strategy, they supported the participants in formulating specific action plans based on identified problems. (Field notes A-1, A-2)	Artefact illustrating different tools packed in a toolbox. (Poster board, programme book)
	Recognising individual expectations	"We [the facilitators] were playing along as well. I mean we were setting ourselves objectives, action plans to complete. And that meant we were showing our weaknesses too". (A-2-14)	"It is an interesting idea, because I think when you have diabetes, you have to take care of yourself and not put all of your trust in doctors. I'm not saying that doctors are bad. I'm saying that patients should take care of themselves." (A-1-19)	The participants expressed their expectations: Some were interested in improving their insights on activities they could do; many, in seeing what others do; and most, in receiving information. The facilitators described their role. (Field notes A-1, A-2)	"Becoming an actor of your own health with a chronic disease." (Programme leaflet)
	Continuing with extended resources	"[Name of the programme] is offered at different places and as a complement to other programmes and strategies. It is regularly advertised, and interested people have the choice to participate in different courses." (A-2-10)	"Having all the local contact details together in a separate booklet was really helpful, especially when looking for information such as where to go for more assistance and further support." (A-1-15)	The facilitators encouraged the participants to read the corresponding content sections in the programme book, to reinforce the group-based learning and to provide some more detailed self-help strategies. (Field notes A-1, A-2)	"The programme book – this book offers valuable information to live a healthy and active life." (Programme description)

### **5.3.1 Using tools in self-management support**

To support participants in personalising self-management in practice and in exchanging their thoughts in the context of the programme, the facilitators referred to a “toolbox of self-management”. Besides strategies such as formulating action plans regarding physical activities, healthy nutrition, regular intake of medication and daily handling of chronic conditions, the programme also used tools to develop transferable skills that participants could use either in living with chronic disease or in their wider experiences of daily life. These areas addressed emotional responses, moods, relaxation, communication styles and possible interactions. The facilitators underlined that the broad variety of strategies in self-management support was needed because not all participants respond to the same strategy:

We talk about a “toolbox”; there are a lot of tools, and we use them to various extents during the sessions ... . There’s self-management – precisely, relaxation. We have short moments of relaxation. There are communication exercises that we do, where we explain how certain tools can be useful in a given situation. Some tools are of no use to anyone: Some people can never enter a state of relaxation or think positive thoughts, though we try to make them turn the negative thoughts they have into something positive ... . So, we work on all those things, short exercises like that, and there is a lot of sharing as well.

(Facilitator interview, A-2-15)

As illustrated, the programme offered participants choices to individualise their self-management, indicating that the programme was adaptive to the personal and experiential level of individual participants.

In discussions, the facilitators underlined the value of non-judgemental interactions and encouraged participants to contribute with their personal perspective. In so doing,

they created a group dialogue in which different experiences could be constructively exchanged so that participants might identify with others' experiences.

In addition to using different techniques by HCPs to encourage patients' self-management behaviour, observational learning was fostered by involving peer facilitators as role models. The advantage of role models was that they integrated some insight strategies of living with disease and emotional responses into the courses so that these experiences could be shared with the participants. For instance, a peer facilitator explained her personal experience implementing treatment schemes:

After all these years and now handling my disease more or less independently, I still have to think about what and when I eat, how to adapt when I do sports, what to take with me when I travel or when I go out with friends ... and although I have more choices with my medication scheme and I enjoy that ... but sometimes I am also tired with all these constraints.

(Facilitator interview, A-2-12)

During this part of group discussion, the peer facilitator contributed more actively to the exchange than the HCP, who only asked questions such as "how was that for you?" so as not to interrupt discussion among participants (field notes, participant observations A-1, A-2). Another frequently used tool was the formulation of action plans, where the facilitators "were playing along as well (facilitator interview, A-2-14). Most participants verbalised action plans pertaining to physical activities, eating habits and relaxation exercises, as reflected by one of the facilitators:

We can share ideas, such as preparing something twice a week for lunch the next day. Start with that. And they start thinking about the following week – will that be possible? Do I have two free evenings at home when I can cook? And you have to visualise and adapt your action plan according to this ... . You have to visualise your week to really be talking about something concrete, which you can then implement day after day.

(Facilitator interview, A-2-15)

The facilitators supported participants in reformulating strategies and helped them to verbalise positive and achievable objectives. In the next session, the participants shared the outcomes of their action plans with the group and either adapted the strategies or formulated new objectives (field notes, participant observations A-1, A-2). Using feedback loops in the programme concretely helped participants to implement their objectives in practice.

### **5.3.2 Recognising individual expectations**

The participants conveyed different reasons for attending the programme. While some participants expected to gain more theoretical knowledge, as expressed, for example, in one person's desire "to get a maximum of information", others sought experiential knowledge regarding "what activities they can do" and "to see what others do" (field notes, participant observations A-1, A-2). These different expectations seemed to be regulated by the participants' educational needs, their previous experiences and exposure to self-management education, as illustrated in the following examples. Some participants chose to participate in this programme because it emphasised their potential to be an active rather than a passive participant, which reflected their own life experience, as captured by this account when asked about motivation to participate:

Its name, "Become an actor of your own health",<sup>4</sup> resonated with me. I am an actor on the side. That word, actor, also means making some choices. When you're an actor in a play, you don't necessarily choose the play, but you decide how to interpret it. In the same way, if you are an actor of your own health. ... I didn't choose that disease, but I can decide how to act it out. That is something that touches me, speaks to me, motivates me and brings me to life. You must be hearing that in my voice.

(Participant interview, A-1-16)

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<sup>4</sup> Original French title: "Devenir acteur de sa santé" avec une maladie chronique

Other participants were less enthusiastic or confident about participating in the programme and revealed that they neither “felt motivated at first” nor “that it was something they needed” (field notes, participant observations A-1, A-2). These participants explained that someone else thought it was good for them. The courses were recommended to them in conversations with social contacts and, on some occasions, as “part of a consultation with the general practitioner” (participant interview, A-1-14).

Others were motivated to participate at first because they expected to improve their self-management strategies. For example, when asked about reasons for taking part in the programme, one of the participants expressed the following:

It is an interesting idea, because I think when you have diabetes, you have to take care of yourself and not put all of your trust in doctors. I'm not saying that doctors are bad. I'm saying that patients should take care of themselves.

(Participant interview, A-1-19)

These participants perceived the importance of actively contributing to their treatment, although some were later slightly disappointed because they expected “more information to follow” (participant interview, A-1-11, A-1-12).

The opinions described above exemplified the broad variety of participants’ expectations that the facilitators needed to take into account in order to ensure that each participant benefitted from the programme to some degree.



### 5.3.3 Continuing with extended resources

In order to provide learning resources outside the group session, the programme included a patient reference book as an extended resource as well as information on additional support options to develop and sustain the participants' learning and personal plans.

For example, the facilitators used some content from the book during the course and encouraged the participants to read "the corresponding sections in the programme book" to reinforce the group-based learning after the session and to provide more detailed self-help strategies (field notes, participant observations A-1, A-2).

While Case A was a stand-alone programme, it was also connected to other regional resources and "was offered at different places and as a complement to other programmes" (facilitator interview, A-2-10) to enhance the self-management behaviour and overall health competencies of people with chronic conditions. Participants could potentially benefit from additional programme offerings, support options and other information accessible through the connection to other cantonal healthcare resources – for example, themed lectures and workshops and individual confidential exchanges with expert patients and health fora, which are regularly conducted within the context of the healthcare system.

As participants' learning needs and preferences changed over time, some participants also accessed other locally offered courses before or after finishing the programme in Case A. Other training courses, for example, focused more heavily on the actual doing of physical activities and less on conversation, as expressed in this account:

With [name of the other programme], you do the exercises ... . So, if you do the exercises, you have a relationship with your body, which is that of exercise ... that's it. This programme isn't like that at all. There aren't actually any exercises; everything is mental.

(Participant interview, A-1-19)

Some participants followed training courses to improve their disease knowledge but voiced difficulties in retaining the transmitted information and applying it in daily practice:

Since diagnosis, I have participated in many courses ... the programme at [name of hospital], where several doctors, nurses, dieticians and others explained diabetes, only diabetes ... . [The programme] was good and we received much information ... but I forgot most of it.

(Participant interview, A-1-11)

In some cases, participants used online learning resources to enhance their factual understanding of their disease. While online courses transferred knowledge independent of space and time limitations, they did not allow for the exchange of personal experiences and were not connected to local context and resources, as illustrated in the following account:

After diagnosis I wanted to learn as much as I could about the disease and subscribed to the online support programme [name of programme] ... that was not bad, but I missed the direct exchange with other people.

(Participant interview, A-1-18)

There was a broad variety of support programmes offered, and participants expressed contentment about receiving information about "all the local contact details together" (participant interview, A-1-15). In addition, they appreciated guidance in navigating through the different options, while learning more about their disease and treatment:

You also need to have a critical mind, an analytical mind, when you're faced with the various suggestions made to you as a patient. You can't take everything at face value. It means improving your everyday life, so you don't depend on others every day.

(Facilitator interview, A-2-11)

Developing self-management behaviour is an ongoing process of learning and adapting to changing circumstances, which can be individually encouraged in a timely manner through combined learning resources beyond a single programme.

#### **5.4 The divergent interests in self-management**

This theme addresses some of the potential challenges to implementing self-management education in routine care. Pertaining to the factors that influence programme delivery and participation, the theme relates to the divergent interests in self-management (see Table 5-4). This theme is based on three sub-themes: varying group dynamics (to describe different interactions), spreading the news (to address the factors that influence programme diffusion), and incorporating context (to adapt programme delivery to the specific environment).

**Table 5-4 Theme 3: The divergent interests in self-management with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme facilitator interview data	Programme participant interview data	Observational data	Documentary data
The divergent interests in self-management	Varying group dynamics	"We had a very large group the first time around, with several people who had a lot to say, and two of them got into a fight. They were both rather aggressive, and it ended with one of them storming out and slamming the door." (A-2-15)	"We didn't really discuss anything important as our backgrounds were too far apart ... for me, my needs were to make myself understood as a person, and they never really understood me as a person." (A-1-19)	Some of the participants were observed to be more reluctant to interact with the group. Others expressed themselves easily, and a few took up a lot of time to express themselves. The facilitators tried to balance that. (Field notes A-1, A-2)	"During the programme, you meet people who are experiencing a similar situation. You become familiar with many techniques and exchange tips and tricks with other participants." (Programme description)
	Spreading the news	"Most participants are ... satisfied with the courses and speak positively about it ... and our colleagues show an interest, as they say, but we still have problems recruiting enough participants." (A-2-11)	"I'm not sure if my GP is interested in this kind of support ... when I told him that I participated in the programme ... he murmured something but didn't really respond ... maybe he doesn't know the programme." (A-1-10)	The facilitators animated the group by asking and rephrasing questions to put everyone at ease. If needed, they broke the ice or cut someone off so that all had the opportunity to express themselves. (Field notes A-1, A-2)	"The programme is offered to people living with chronic disease, their families and friends and anyone who is a healthcare or social professional." (Programme description)
	Incorporating context	"I adapted the content in my way of talking about it. I pick my own words, I say it my way. That happened very early. I just didn't use the script, so that was it. ... I talk." (A-2-15)	"Probably as soon as the second session we no longer felt like they and we ... we were a group. We both learnt, and it didn't feel like a course, at least not like a lecture." (A-1-17)	The facilitators combined expressions describing individual experiences in specific situations. Then they noted those on a flip chart: for example, stress and medication scheme and multidisciplinary team. (Field notes A-1, A-2)	"The programme judiciously complements other offers of medical and therapeutic care. Health support is always a team effort." (Programme description)

#### **5.4.1 Varying group dynamics**

Varying group dynamics emerged from the interactions of the participants that influenced their perceptions of the programme. Some may not have found common ground for an exchange due to different interests as they perceived their personal needs were not being addressed in the group as was voiced in the following account: "We didn't really discuss anything important as our backgrounds were too far apart ... for me, my needs were to make myself understood as a person, and they never really understood me as a person" (participant interview, A-1-19).

Furthermore, group dynamics may also result in challenging experiences for the facilitators. This occurred, for example, because the programme involved discussing personal experiences that could bring up strong emotions. Moreover, the size of the group and different personalities present in the group influenced group interactions. This is illustrated, for example, in the account of an experienced facilitator describing a situation in which two participants got into an argument: "We had a very large group the first time around, with several people who had a lot to say, and two of them got into a fight. They were both rather aggressive, and it ended with one of them storming out and slamming the door" (facilitator interview, A-2-15).

Indeed, emotional outbursts might occur in these types of interactions, especially when the theme discussed is personally close to someone. Another potential consequence was the emotional transfer between participants who empathised with others' lived experiences. While sharing experiences was an asset of the programme, working with people in close interactions might also cause distress:

I take a lot on myself too. It's something I should handle as well. [Laughter] It is always rich in emotions. It is an exchange, a way of learning. I learn a lot from others but sometimes I also take their sorrows on me ... and then I have to deal with that.

(Facilitator interview, A-2-12)

These examples illustrate the need for facilitators to develop strategies on how to handle varying group dynamics and issues that they or other participants may experience, which also demands for HCPs' additional training and support.

#### **5.4.2 Spreading the news**

The programme was mostly promoted through word-of-mouth advertising and through directly contacting primary care providers. However, interacting with engaged and informed participants might be a challenge for some HCPs because such interactions imply that participants expect to learn from HCPs' experience rather than being lectured at – an exchange that requires different skills. Some HCPs may perceive resistance in adopting a different care approach and although "they show an interest, as they say" (facilitator interview, A-2-11), limit the programme diffusion for recruiting potential participants.

For a number of participants, the programme paradigm also diverged from their prior learning experiences because some were accustomed to being told what to do by HCPs. While most were satisfied with the novel approach, a few participants experienced discomfort when the facilitators worked hard to avoid giving advice, which can be an unusual experience for participants (field notes, participant observations A-1, A-2). These participants needed encouragement to engage in the different approach to learning. One peer facilitator voiced this as follows:

We [patients] share things as we live them on a daily basis, and I think it's important to be attentive. In the end, we [patients] are the ones making most choices. And that's how we can better move forward with the treatment.

(Facilitator interview, A-2-12)

Participating in the programme may encourage patients to actively interact in shared decision-making with HCPs. In addition, the programme was also open for HCPs to get acquainted with the content as was mentioned in the programme description.

However, the challenges of integrating the programme concept into the continuity of patient care were still unresolved, as expressed by one of the participants:

I am not sure if my GP knows that I participated in the programme ... when I asked him he murmured something but did not really seem to be interested ... maybe he doesn't know the programme. He only asked me if I eat better now.

(Participant interview, A-1-10)

As suggested in this account, the approach of different HCPs who work in other parts of the healthcare system may challenge the success of such self-management education programmes. Furthermore, the fact that primary care providers do not take into account programme participation was perceived as a potential source of frustration for participants, thus hindering the optimal use of the programme and diminishing its potential for improving self-management.

#### **5.4.3 Incorporating context**

In addition to the delivery of the programme content, the facilitators adapted the programme to reflect the participants' backgrounds. In doing so, the facilitators used everyday language and adjusting their expressions to adopt the phrasing used in the group discussions, rather than reverting to their specialist language. For example, they used the expressions of the participants, instead of only following the programme script (field notes, participant observations A-1, A-2). This adaptation to the context increased the facilitators' authenticity and, to some extent, indicated that the facilitators shared power with the participants. While the facilitators had control over the group, they did not assert their professional authority; they worked within the group rather than on the group. Hence, the facilitators modified their communication style and used words and expressions that were common in the socio-cultural context of the participants. For example, one of the facilitators stated the following:

I adapted the programme content in my way of talking about it. I pick my own words, I say it my way. That happened very early, I just didn't use the script, and that was it. There are words that need to be used. I think they are very vivid expressions such as "journey through life", "ups and downs", all these. They [the authors of the programme] insist that you use certain terms like these, so I use them, but I don't read the text: I talk.

(Facilitator interview, A-2-15)

By adjusting their language for the participants in the group discussions, the facilitators were able to adjust the programme content to the individual backgrounds and experiences of the group members. This aspect was recognised by participants:

We are from different backgrounds, but it didn't matter at all ... . How do I put this? Yes, that's it really, your background, how you've been living, how you live now, your social status and your way of life. What was remarkable is that it never came up. You could sometimes feel it in the way people talked, we could, but that never came into play within the course itself. I thought it was rather extraordinary. I think that came from the group, and from the facilitators – it was both.

(Participant interview, A-1-16)

Probably as soon as the second session we no longer felt like they and we ... we were a group. We both learnt, and it didn't feel like a course, at least not like a lecture.

(Participant interview, A-1-17)

The facilitators created an open, inclusive atmosphere so that participants felt at ease to express their thoughts and experiences and thus, they perceived themselves as part of the group. Hence, the programme fostered a group learning experience in an environment of belonging where participants shared a common purpose.



## **5.5 Summary**

This chapter shows that integration in Case A is related to creating a supportive environment that fosters mutual learning of patients and HCPs through valuing experiential and professional expertise. Such exchange supports patients in sharing their symptoms of chronic disease so that they may find meaning in their personal experiences. This identification contributes to the development of individual self-management behaviours while, at the same time, considers the divergent interests that may influence self-management.

The group exchanges and shared reflections on participants' conditions and treatments facilitated an experience of social support. These considerations supported them in deriving new meaning from their experiences, which in turn helped them relate their self-management behaviour to their condition and activity. This process may encourage patients to integrate their personal experiences and perceptions into their self-management behaviours, which then could support them in living with their conditions. Equal importance was assigned to individuals' perceived experiences of living with a condition and to professional, theoretical expertise of the disease. Such interactions resulted in mutual learning occasions for both patients and HCPs (programme facilitators), thus enriching the programme delivery and participation. Facilitators with lay and professional training were mostly satisfied with the programme paradigm of sharing individual expertise. However, this kind of interaction had not been integrated into the continuous care delivery of all participants, and some experienced frustration due to not receiving the same support in routine care.

## **Chapter 6 Case B – Increasing physical activity and disease understanding**

This chapter presents the main findings of Case B. As in the previous chapter, it begins by setting the scene for the programme, which is important for contextualising the themes. The themes pertain to how the nature of integration relates to the programme features of Case B, the strategies that encourage the adoption of an active lifestyle and the competing interactions in everyday life that affect the implementation of an active lifestyle. The specific meaning of integration within this case is captured in the themes and sub-themes, which are validated with data excerpts to show cross-connectivity. As in the previous case, the data excerpts follow in the presentation of each theme. The overall thematic structure is summarised in Table 6-1.

**Table 6-1 Themes and sub-themes in Case B**

<b>Themes</b>	<b>Sub-themes</b>
The nature of integration in Case B	<ul style="list-style-type: none"><li>• Combining lifestyle with diabetes</li><li>• (Re)learning to be physically active</li><li>• Enjoying activity</li></ul>
The adoption of an active lifestyle	<ul style="list-style-type: none"><li>• Using strategies to be more physically active</li><li>• Sustaining motivation for physical training</li><li>• Training with peers for support</li></ul>
The competing interactions in everyday life	<ul style="list-style-type: none"><li>• Recognising multiple challenges to being physically active</li><li>• Adapting to individual health conditions</li><li>• Creating situations that improve habits</li></ul>

## **6.1 Setting the scene for the programme in Case B**

This section begins by characterising the typical setting within which participants trained and interacted. This programme involved different HCPs presenting workshops and accredited programme instructors running the exercise sessions.<sup>5</sup> These instructors were certified sports therapists or physiotherapists who were trained for the delivery of this programme.

The programme combined sessions of different kinds of physical activities and themed workshops for discussing type 2 diabetes and treatment strategies over a period of 12 weeks. The participants were initially registered in the programme by their general practitioner or diabetologist. Because the programme addressed people with type 2 diabetes and cardiovascular risk factors, participants underwent medical exams before and after the programme to test their physical condition.

In addition to physical training, the exchanges and interactions between participants were an important component of the programme. The instructors facilitated group discussions between participants to encourage social learning, which was used as an additional support strategy in these courses.

Vignette 6-1 outlines a typical session of the programme. Most sessions were similarly staged to create an appealing environment in which men and women trained together under the supervision of an instructor. Similar to the facilitators in Case A, the group instructors in this case also encouraged the participants to be active and to discuss their experiences with their training companions for mutual support.

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<sup>5</sup> Original term in French: “des moniteurs accrédités par le programme”

### **Vignette 6-1 Synopsis of typical training sessions in Case B**

A group of people with type 2 diabetes met three times during the week for training. They participated in different indoor and outdoor exercises to enhance their level of physical activity. Sometimes they stayed afterward for a workshop to learn more about their condition.

Some of the participants were actively exchanging ideas and experiences with the other participants from the beginning of the course, while others seemed reluctant to talk or move in front of people.

The programme instructors reassured the participants that everyone's efforts and contributions in these training sessions were valuable. For example, when one of the participants expressed concern that he slowed his pace when he felt exhausted while walking, the instructor related this to the group by underlining that reducing his rate was good and that everyone needed to do the same in such a situation.

The instructors were observed to adapt the training programme to the individual physical condition of the participants, but they also encouraged the participants to continue with the training. For example, the following exchange between one of the instructors and a participant was observed: "If you don't achieve something right away, try to do it step by step, and gradually you will succeed to do that".

Although the professionals who trained the participants were called instructors, they were not perceived as acting in the traditional way of commanding that is often associated with this role. Instead, the participants recognised them more as coaches. For example, one participant said, "The instructor we have seems to be very sympathetic", and another responded ironically: "Yes, we don't need a corporal or army captain, thank you very much".

(Field notes, participant observations B-1, B-2)

## **6.2 The nature of integration in Case B**

This theme illustrates how the programme instructors and participants with T2DM perceived integration in Case B. Furthermore, it presents how integration developed within the programme, as observed over the course of the sessions and represented in the course documents. The data revealed key features of integration that show how the programme encouraged participants to increase their level of physical activity and disease understanding. These features relate to combining lifestyle with diabetes, (re)learning to be physically active and enjoying activity.

A key feature of the programme was to connect the knowledge of the beneficial value of exercise (theory) with its execution in daily routines (practice). This enabled the individuals to reconnect with their physical being and integrate exercise into their lives, as illustrated in their accounts below. Another foundational aspect of the programme related to people's perceptions when they started physical training. Although people in a poor physical condition may often initially experience unpleasant sensations when starting a fitness program, the participants gradually adopted new behaviours and regained confidence in their bodies by (re)learning to be physically active. The participants expressed a better perception of their physical and mental states, which was reinforced by the pleasure doing such activities gave them. In this sense, this case emphasised the integration of activity and practices of personal health (lifestyle) for people with diabetes. An overview of the theme and sub-themes is detailed with excerpts of supporting evidence in Table 6-2.

**Table 6-2 Theme 1: The nature of integration in Case B with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme instructor interview data	Programme participant interview data	Observational data	Documentary data
The nature of integration in Case B	Combining lifestyle with diabetes	"The programme is based on four pillars. One of these pillars in particular is education. There is the medical part, the physical activity part, the nutrition part and then this education part." (B-2-10)	"It's a whole array of things that have an impact. ... It's not just the pills, not just the physical activity. It's how you eat, move every day, it's walking up the stairs, going for a swim. It's all those things." (B-1-13)	Some of the participants interacted openly with their training companions and HCPs from the start of the programme, while others were more reluctant and needed more encouragement to interact. (Field notes, B-1, B-2)	"This programme is provided by a multidisciplinary team ... . Physical activity sessions are offered together with interactive workshops to enhance your knowledge." (Programme leaflet)
	(Re)learning to be physically active	"For the majority of patients, it's the first time in a while that they start to move and at first, it's difficult. ... [For them,] it is to regain confidence." (B-2-16)	"And that caused a lot of pain at first, but I realise now that I can do a lot more with a lot less pain, so that's motivating." (B-1-14)	At the beginning of the course, some participants were observed to be exhausted after a few minutes of exercising and paused. Then they restarted at a slower pace guided by the instructor. (Field notes, B-1, B-2)	"Regular physical activity has a beneficial effect on cardiovascular risk and well-being." (Programme leaflet)
	Enjoying activity	"There is an improvement, maybe not in terms of weight, but that wasn't really the programme's goal. But they are more flexible, more agile; they gain in flexibility. They seem to be happier, I would say." (B-2-19)	"I could say, within the programme's timeline, I was much less dynamic than I am now. In terms of tone, of muscle, I've grown stronger. ... And I like that, I feel much better." (B-1-18)	After a few sessions, most participants observed that exercising seemed to be easier for them; they chatted with each other while walking or exercising, and some were joking. (Field notes, B-1, B-2)	"Encouraging physical activity is part of the overall care of diabetic patients." (Programme description)

### **6.2.1 Combining lifestyle with diabetes**

The participants' exposure to the programme facilitated a learning process in which they gradually recognised their potential to be more active while also dealing with the perceived constraints of living with their condition. Most participants described how this helped them understand more about their disease and its influence on their sense of well-being. Some of them began to recognise how their day-to-day activities influenced their diabetes, as characterised in the following accounts by two programme participants:

It's a whole array of things that have an impact. ... It's not just the pills, not just the physical activity. It's how you eat, move every day. It's walking up the stairs, going for a swim. It's all those things.

(Participant interview, B-1-13)

"I'm aware that this programme has taught me that everything from my behaviour – from what I eat to how I move – is important. I learnt to look at my condition in a more holistic way.

(Participant interview, B-1-18)

As indicated in these examples, the programme helped the participants understand the connections between physical activity and other factors, such as adapting eating habits and taking medication, as all these interactions may influence their health conditions. The programme philosophy espoused these factors as strategies to enhance physical activity because understanding the demands of living with the disease might make it more likely that the participants will alter their behaviour. The programme strategies addressed different areas, described in the following account:

The programme is based on four pillars. One of these pillars in particular is education. There is the medical part, the physical activity part, the nutrition part and then this education part.

(Instructor interview, B-2-10)

The educational component refers to learning about the interacting mechanisms of treatment strategies, so participants could better understand how to influence the disease and its symptoms. The combined programme components of theory and practice supported the participants in more autonomously handling their day-to-day activities of disease treatment, as illustrated in the following example:

What I mean is that, as part of the programme, it is on learning about physical activity. ... So, they make connections with everything linked to [diabetes] ... and set up all these different elements so that the programme would not be just a therapy coming from the top but also a way to learn things, to make them [the participants] independent in the handling of their disease. It is giving them tools for that.

(Instructor interview, B-2-17)

In this sense, the programme used an integrated range of interventions to encourage the participants to incorporate physical activity again into their routines as part of adopting a healthier lifestyle.

### **6.2.2 (Re)learning to be physically active**

For different reasons, most of the participants had not been doing any regular physical activity for a significant period of time and needed to integrate more physical activity into their daily activities to improve their health condition. While the programme underlined the beneficial effects of physical activity on cardiovascular health and well-being, many participants initially perceived discomfort or even pain when moving more. While the impact of physical activity on health conditions is favourable overall, people may initially find it to be a struggle and experience some negative sensations.

Especially at the beginning of the training sessions, some participants also expressed that they felt insecure about their physical capabilities as they suffered from different ailments such as shortness of breath or pain when they exerted themselves in sports



activities. Some of them were unaware of what they would be able to do as they had not exercised for a long time:

For the majority of patients, it's the first time in a while that they start to move, and at first, it's difficult ... [for them]. It is to regain confidence. ... It's also important how they do the exercise and the way they move.

(Instructor interview, B-2-16)

And that caused a lot of pain at first, but I realise now that I can do a lot more with a lot less pain, so that's motivating.

(Participant interview, B-1-14)

The data suggest that supervised training with progressive adaptation to the participants' physical condition helped them to overcome the difficulties they experienced at the beginning of the programme.

### **6.2.3 Enjoying activity**

The programme encouraged physical activity as part of the overall care for people with T2DM. In addition to the more informative exchanges with the multiple HCPs in the workshops, informal exchanges with training companions were a helpful aspect of the programme for supporting the participants in enjoying the activity.

In the course of the programme, most participants experienced an improvement in their physical condition as a direct consequence of their training effort. The training effect contributed to a better body composition, which pleased them:

I could say, within the programme's timeline, I was much less dynamic than I am now. In terms of tone, of muscle, I've grown stronger. ... And I like that. I feel much better."

(Participant interview, B-1-18)

The overall improvement in the participants' physical condition was also affirmed in the accounts of the programme instructors. As the focus was on increasing physical activity and disease understanding, weight loss was not the priority of the programme, as voiced in the following example:

So, there is an improvement, maybe not in terms of weight but that wasn't really the programme's goal. But they are more flexible, more agile; they gain in flexibility. They seem to be happier, I would say.

(Instructor interview, B-2-19)

As implied, most participants experienced improvements in their physical condition and better perceptions of life. The positive experiences were further enhanced because the programme exerted no pressure on the participants to lose weight. This suggests that the worth of the participants was not reduced to their body weight; therefore, they were not branded as failures if no weight loss was observed. Nevertheless, a possible weight loss could occur as a result of the improved level of physical activity and an overall healthier lifestyle.

The data also suggests that by improving their overall health, some participants regained their spirits, which in turn encouraged them to like the training, as one of the participants voiced proudly:

Me, I always did the same back and forth between my living room and the fridge, and now I am more flexible, and I can go for a walk in the park rather than going to the fridge.

(Participant interview, B-1-11)

In this sense, the programme encouraged the participants to associate their training activities with pleasure, and the prevailing positive emotions better supported the participants in integrating physical activity into their daily behaviours.

### **6.3 The adoption of an active lifestyle**

The theme of the adoption of an active lifestyle presents the different learning strategies and stimuli identified in the data that helped participants to adopt an active lifestyle and integrate physical activity into their normal routines. The theme is based on the programme features that characterise the following sub-themes: using strategies to be more physically active, sustaining motivation for physical training (through evaluation) and training with peers for support. The overview of the theme and sub-themes is illustrated with excerpts from the data sources in Table 6-3.

**Table 6-3 Theme 2: The adoption of an active lifestyle with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme instructor interview data	Programme participant interview data	Observational data	Documentary data
The adoption of an active lifestyle	Using strategies to be more physically active	"It is the way in which all the components of the patients' treatment are set up ... it is a task focused on learning about physical activity. It is not only to make them move but also to share information." (B-2-16)	"Moving more, getting a better understanding of diabetes ... it was about working together, seeing other people living with the same issue. I'm very drawn by the group aspect." (B-1-17)	The participants exchanged their training experiences and discussed strategies to overcome difficulties. Most were observed to share their experience within the group by expressing how they felt in the training. (Field notes B-1, B-2)	"Improve your quality of life and learn how to better manage your diabetes." (Programme leaflet)
	Sustaining motivation for physical training	"Because we really do test their blood sugar before and after exercising, so we show them the effects of activity on their diabetes ... and this is motivating." (B-2-10)	"When I make an effort now, I know it's a positive thing for me. I know I'm being good to myself. I know it's very positive." (B-1-19)	The participants checked and discussed their blood glucose before and after each training session; one was observed to say with surprise, "I don't understand why at times my values are higher after training." (Field notes B-1, B-2)	"The clinical evaluations of the patient (physiological parameters, motivation, physical condition) are conducted at the beginning and at the end of the programme." (Programme description)
	Training with peers for support	"There is a whole dynamic within this group and some of them even stayed together to be active, they see each other again [for walking]. ... I think it's one of the main goals." (B-2-19)	"It's great as well to be meeting other people. Now I sometimes walk with someone else on the programme, but it's our own decision, and it creates a friendship, and it's also a way to push each other." (B-1-15)	Some were observed as saying that they had arranged with a colleague to train outside the course. They said that it was easier to train that way as walking and talking together was a pleasure. (Field notes B-1, B-2)	"Physical activity in a group and in a good atmosphere to stay fit or to regain it [fitness]." (Programme leaflet)

### **6.3.1 Using strategies to be more physically active**

This sub-theme presents some of the programme mechanisms that encouraged people with T2DM to take up physical activity. The strategies used in the programme formed the participants' learning experiences, which developed from the ways the programme components interacted, as expressed in the following accounts:

It is the way in which all the components of the patients' treatment are set up ... it is a task focused on learning about physical activity. It is not only to make them move but also to share information.

(Instructor interview, B-2-16)

Moving more, getting a better understanding of diabetes ... it was about working together, seeing other people living with the same issue. I'm very drawn by the group aspect.

(Participant interview, B-1-17)

Actually doing physical activities was the main strategy used in the programme. These activities were supervised in the training sessions by the group instructors, who were observed, for example, to give clear guidance on how to walk with the Nordic walking sticks, to do the exercises or to use the machines. The clear instructions supported the participants in precisely executing the movements in order to achieve the desired training effect. This was important because some of the participants expressed difficulties in coordinating their movements, and a few said that they felt clumsy when exercising (field notes, participant observation B-1, B-2).

Another strategy was the theoretical input provided by the HCPs in the workshops. Besides giving information, some of the HCPs opened up the session to include different issues raised by the participants as a way to foster interactive discussions. For example, in the workshop on healthy nutrition, the HCPs encouraged the

participants to bring in examples from their experiences. In response, some participants freely did so, while others looked somewhat puzzled, as if they would have preferred more exact advice and guidance (field notes, participant observations B-1, B-2). Those latter participants expressed difficulties with the participative style used in that workshop when asked about the delivery mode, as indicated in the following:

It was interactive, in the sense that they asked us what we thought of something ... some people thought that this was useless as finally we had learnt nothing at all. ... We got a few sheets but nothing concrete. ... I found that there was no structure, that this was not clear. ... I'm perhaps too harsh.

(Participant interview, B-1-11)

As implied, some participants preferred receiving information in a structured written form and expressed less interest in sharing their experiences within a group. Others liked exactly that aspect of sharing in the group:

That [sharing] is rather positive because sometimes I forget to ask a question, but as someone else is asking a question, I can still get an answer.

(Participant interview, B-1-12)

The course delivery in groups encouraged another strategy used in the programme, peer support. Some of the participants formed smaller sub-units for individual training; they were observed training together and discussing their training experiences. Others were observed to create informal groups for discussion. For example, one participant described how training with others who experience similar issues helped him because he felt supported and understood (field notes, participant observations B-1, B-2).

The data suggest that the different strategies used in the programme supported the participants in increasing their activity levels. As illustrated in the above examples, the participants trained, interacted and learnt in the group interactions to become more aware of possible ways for them to influence their own conditions. This enabled them to improve their physical activity and to create benefits for their health and quality of life.

### **6.3.2 Sustaining motivation for physical training**

The programme also supported the participants in directly perceiving the influences of their own activities on the management of diabetes in order to better understand how their training affected their condition. For example, the programme encouraged the participants to consider how their bodies reacted to the physical movements. In this regard, most described feeling better after a few training sessions and said they experienced less discomfort when doing exercises (field notes, participant observations B-1, B-2). This was also conveyed in the following comments when both participants and instructors were asked to describe their programme experiences:

And this is where the programme is interesting because they [the participants] feel for themselves how it works.

(Instructor interview, B-2-10)

When I make an effort now, I know it's a positive thing for me, I know I'm being good to myself, I know it's very positive.

(Participant interview, B-1-19)

These examples suggest that many participants experienced a direct physical benefit to their condition during the training. Moreover, their overall improved perceptions of their health motivated the participants to continue their training. In addition, the structured glucose measurements supported the participants in directly evaluating the effect of the training on their metabolism, expressed as follows:

Because we really do test their blood sugar before and after exercising, so we show them the effects of activity on their diabetes ... and this is motivating.

(Instructor interview, B-2-10)

The participants also used their blood glucose values to enhance their disease knowledge as they discussed the effect of physical activities with the instructor and the group. For example, some participants were observed to be perplexed that at times their glucose values were higher after training, and the group discussed possible causes for the increase (field notes, participant observations B-1, B-2). This indicated that such direct exchange improved their understanding and prevented a seemingly paradoxical increase of blood glucose from negatively affecting their motivation to exercise.

Furthermore, the participants were informed that the programme included a clinical evaluation of different physiological and psychological measurements at the beginning and the end to assess their progress during the programme. Some participants experienced health conditions with a high level of risk. By adapting physical activities to the participants' individual health conditions, they were encouraged to gradually build up their training to avoid damaging their health or losing their motivation due to overly difficult training.

In this way, the programme supported the participants in slowly progressing towards achieving their individual training goals and furthered their overall improvements by sustaining their motivation for physical training.



### **6.3.3 Training with peers for support**

Some participants were observed to create small groups for training to build mutual support. For example, some always walked with the same people and sat beside each other during the workshops (field notes, participant observations B-1, B-2). After a few sessions, most of the participants were observed to chat more with each other while walking or doing the exercises, and some joked with each other (field notes, participant observations B-1, B-2). Many participants felt supported by their training companions due in part to the fact that some experienced similar difficulties when doing physical activities related to their condition. The social bonding within the peer group also encouraged the participants to continue their training outside the programme and to connect with others for additional walking. At times, the sharing of experiences created a bond between some of the participants to further friendship. These relationships encouraged them to expand their training and to make an additional training effort:

It's great as well to be meeting other people. Now I sometimes walk with someone else on the programme, but it's our own decision, and it creates a friendship, and it's also a way to push each other.

(Participant interview, B-1-15)

The social space developed in the programme supported the participants to do physical activities within an encouraging atmosphere, as voiced in the following account:

There is a whole dynamic within this group, and some of them even stayed together to be active. They see each other again [for walking]. ... I think it's one of the main goals.

(Instructor interview, B-2-19)

In this sense, joining a training group with peers furthered the human interactions that encouraged the participants to develop a sense of camaraderie, which helped them to continue with physical activities and to adopt an active lifestyle. As a result, the peer support enabled them to build confidence as they re-integrated physical activity into their lives.

#### **6.4 The competing interactions in everyday life**

The theme of competing interactions in everyday life captures some of the challenges that hindered people from adopting an active lifestyle. The sub-themes relate to recognising multiple challenges to being physically active, adapting to individual health conditions and creating situations that improve habits. Understanding these aspects helped participants to integrate their programme learning and experience into their everyday lives. An overview of the theme, sub-themes and data excerpts is detailed in Table 6-4.

**Table 6-4 Theme 3: The competing interactions in everyday life with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme instructor interview data	Programme participant interview data	Observational data	Documentary data
The competing interactions in everyday life	Recognising multiple challenges to being physically active	"I had been practising for a long time with patients with chronic illnesses, and I noticed throughout this journey that prescribing physical activity was something complex." (B-2-17)	"When you're alone and you think to yourself, 'How about a walk?' But you look out the window: It's raining, and you don't go. Or you don't feel like it, or there is a game on, or you want to read a book. You don't go." (B-1-16)	They voiced different reasons for being physically inactive: Many said they had other life priorities (work and family commitments), others perceived their condition not to be serious and some never really enjoyed doing sports. (Field notes B-1, B-2)	"Just a little diabetes, that does not exist." (Programme leaflet)
	Adapting to individual health conditions	"We are interested in their general well-being ... . If some people report pain in their back, their knee, we will take it into account and adjust our approach. Sometimes, the pain can improve; they feel physically better." (B-2-10)	"Given our health condition and our age, I think the people who were leading the activities were very good at adapting to us ... . We all have our limits, or on days and off days." (B-1-14)	Some of the participants told their training colleagues that they felt safer doing physical activities in a group with people and HCPs as they had risk factors that might affect their training. (Field notes B-1, B-2)	"To enable the patients to initiate a physical activity supervised by a specialised multidisciplinary team." (Programme description)
	Creating situations that improve habits	"It allows them to form relationships – and this is self-motivating ... to create a bond in a way ... . It is also our role to encourage these connections. It doesn't happen on its own either." (B-2-19)	"[To remain motivated,] I'd need to stay in a group, to be part of a team. You always think that you'll start on your own ... but the group effect helps. Not only for the exercising part, but mentally as well." (B-1-13)	Some of the previous participants joined in for walking once a week or used the gym for exercising. Others built small training groups outside the programme. (Field notes B-1, B-2)	"A follow-up group will support those who would like to continue to train in a group." (Programme leaflet)

#### **6.4.1 Recognising multiple challenges to being physically active**

The participants voiced different reasons for being physical inactive, but many said that they have had other life priorities. Some participants conveyed that their family or work commitments were demanding and that those time limitations hindered any regular physical training. In addition, while chatting together, the participants were observed to give other reasons, such as never really enjoying doing sports or never thinking that their condition would be serious (field notes, group observations B-1, B-2). As the examples illustrated, people raised manifold reasons for being sedentary, such as following their more pleasurable interests when these coincided with their intention to do physical activities. For example, some participants preferred doing the activity that they perceived to be more enjoyable if they had to choose, as expressed in the following account:

When you're alone and you think to yourself: "How about a walk?" But you look out the window: It's raining, and you don't go. Or you don't feel like it, or there is a game on, or you want to read a book. You don't go.

(Participant interview, B-1-16)

In addition to reflecting their own challenges, it is also important, that the participants recognise possible solutions to help them overcome these challenges. By drawing their attention to their condition and underlining the role that physical activity plays, the programme supported the participants in this adaptation process towards a more active lifestyle. For example, by raising their awareness on a condition that is serious because "having just a little diabetes does not exist" (programme leaflet), but some people may still believe that.

As expressed by the HCPs, simply telling people to move more was rarely sufficient. Instead, they needed a structured approach to support them in the processes of adaptation:

The incentive to set up the group programme was mainly the fact that I had been practising for a long time with patients with chronic illnesses, and I noticed throughout this journey that prescribing physical activity was something complex. And engaging in a physical activity requires a framework, support, specific training ... and it also fits in with the institution's goal, which is a rehabilitation centre.

(Instructor interview, B-2-17)

The data also suggest that the challenging process of adopting a healthier lifestyle could be furthered by the structured programme approach integrated into the overall purposes of a local organisation. The programme fitted with the organisational aims of the delivery settings in the community, which had invested time and resources in the set-up of these courses and for the specific training of the programme instructors.

In this sense, the structured approach supported the participants in recognising their competing interests in their everyday lives so that they could better integrate their training by raising the priority they gave to physical activity.

#### **6.4.2 Adapting to individual health conditions**

The participants had been diagnosed with T2DM and presented different cardiovascular risk factors. The programme enabled the participants to initiate physical activity supervised by a specialised multidisciplinary team, which was alert to the participants' risk factors. Although all participants' health conditions allowed them to exert their cardiovascular system, some felt safer training in a group and with HCPs to contact, if necessary. While engaging in their training, some of the participants were observed to discuss their experiences and concerns with each

other. For example, a few told their training companions about their worries. Some expressed that they did not feel at ease walking alone, although their general practitioner had given them permission to do so. Thus, having a partner and the overall support of the programme helped them gain the confidence to walk (field notes, participant observations B-1, B-2). While it was not clear whether they would sustain the activity on their own after the programme, at least they knew they could do so without significant health consequences.

In the programme, the instructors adapted their training approach to the individual health conditions of the participants. They were observed as first always addressing all the participants as a group and then going to each of them to see how they were managing the physical activity. If necessary, the instructors adapted the training, as voiced in the following account:

We are interested in their general well-being. ... If some people report pain in their back, their knee, we will take it into account and adjust our approach. Sometimes, the pain can improve; they feel physically better.

(Instructor interview, B-2-10)

This example also suggests that participants who experienced a beneficial effect to their general well-being were encouraged to continue their training, which underlines the importance of continuously adapting the training to individual conditions.

Most participants perceived that the programme was well adapted to their needs and felt well supported by the training instructions adjusted to their actual physical form, as expressed in the following statements:

Given our health condition and our age, I think the people who were leading the activities were very good at adapting to us. ... We all have our limits, or on days and off days.

(Participant interview, B-1-14)

They [the instructors] were taking everything with composure and tuning in to our personal situations. They could feel what our needs were as well as our limitations. That's important. Some days you just don't feel right at all; some days you're fine."

(Participant interview, B-1-16)

The programme delivery consisted of collective support and individual encouragement. Most participants recognised that the instructors balanced these two aspects, and although participating in group training, they experienced the instructors as responding well to their individual needs, as illustrated in the following example:

They [the instructors] were achieving a balance between the collective aspect, which is important, and the individual aspect as well. For example, during walks, they would never stay with just one person: They would go from one to the other.

(Participant interview, B-1-17)

As the data suggest, the adaptation of the programme to the participants' health conditions encouraged them to actively participate in the group training and thus possibly enabled favourable training experiences that furthered the likelihood of them integrating physical activities into their everyday lives.

#### **6.4.3 Creating situations that improve habits**

In addition to what was discussed in the previous sub-themes, peer support and group learning fostered the improvement of habits. Some participants raised concerns about their ability to continue the training on their own, especially in the mid and long term. They felt that the sociable atmosphere in the group nurtured their progress, as illustrated in the following thoughts of a retired participant:

[To remain motivated,] I'd need to stay in a group, to be part of a team. You always think that you'll start on your own ... but the group effect helps. Not only for the exercising part, but mentally as well.

(Participant interview, B-1-13)

This example also shows that some participants were principally attracted to joining the training group because it helped them to stay connected to other people after they had experienced changes in their life structure.

In order to further foster social support, the programme also offered a separate follow-up group that was available to all participants for a small monthly fee. As observed in some of the training sessions, former course participants joined in the walking group once a week or used the gym to exercise. This demonstrates that the programme conditions helped participants continue their training and adopt a healthier lifestyle with more physical activities. In the courses, the programme instructors were observed to nurture social exchanges by encouraging participants to build relationships with each other. For example, some of them organised informal gatherings, such as common coffee times before or after the training session or a joint dinner to celebrate the achievements at the end of the programme. At some of these gatherings, both current and previous participants were present (field notes, participant observations B-1, B-2). The importance of social support in the training programme was identified to motivate the participants to connect with each other. This motivation encouraged them to regularly join the group for continuous training because they also perceived their training as a kind of social gathering, as expressed in the following:

It [social exchange] allows them to form relationships – and this is self-motivating ... to create a bond in a way... . It is also our role to encourage these connections. It doesn't happen on its own either.

(Instructor interview, B-2-19)



This example also underlines the value that people give to being social and how such connections fostered their active participation in the training. Social relationships strengthened interpersonal bonds and helped participants continue training outside the course sessions. In this sense, the programme created situations that supported the participants in integrating physical activities into their habits, which in turn also nurtured a healthy lifestyle.

## **6.5 Summary**

The data from Case B underline the importance of supporting people living with chronic diseases to develop the confidence and capacity to integrate physical activity into their daily lives. Through combining theoretical knowledge and active training, the participants felt encouraged to adapt their lifestyles. It is evident that once participants became more active, many felt that it benefitted their health and functioning. The data also reveal the multiple challenges that hinder this population from starting a routine of physical activity and some strategies to overcome these barriers. Combining different strategies may support and motivate the participants to continue physical activities, especially when engaging with training companions.

While the supervised and adapted physical training initially reassured participants to start and then continuously increase their activity despite their health risks, the social bonding within the training groups supported them in continuing their training with peers. In this sense, in Case B, integration occurred by connecting adapted physical activity with theoretical understanding in order to create favourable conditions. These conditions, when combined with social support from peers, improved habits and sustained motivation to continue with the training.

## Chapter 7 Case C – Reflective practice to build relationships and care networks

This case was unique from the others because its participants were HCPs. As above, this chapter begins by setting the scene for the programme and then describes the themes and sub-themes that emerged from the data analyses. While the main themes are similar to those identified in the other cases, the sub-themes of this case are unique and express the meaning of integration within the case that relates to the HCPs skills training. The overall thematic structure, with themes and sub-themes, is summarised in Table 7-1.

**Table 7-1 Themes and sub-themes in Case C**

Themes	Sub-themes
The nature of integration in Case C	<ul style="list-style-type: none"><li>• Developing and sharing values in self-management support</li><li>• Assigning meaning to care in support</li><li>• Identifying essential elements in therapeutic relationships</li></ul>
The creation of person-centred care	<ul style="list-style-type: none"><li>• Using tools to support therapeutic patient education</li><li>• Adopting self-reflection as a concept</li><li>• Building a team for support</li></ul>
The competing paradigms of care	<ul style="list-style-type: none"><li>• Recognising complexity in interactions of support</li><li>• Understanding prevailing mindsets</li><li>• Congruity of the culture of care</li></ul>

## **7.1 Setting the scene for the programme in Case C**

In this programme, the group leaders were observed to use the term “caregivers”<sup>6</sup> to describe all HCPs involved in the care of people with chronic conditions instead of addressing individual professionals by their formal titles. In so doing, they sought to underline every team member’s function and approach towards patient care independent of his or her specialisation. Thus, the generic term was used to generate a sense of inclusivity across the different disciplines, to emphasise the need for a common frame of reference in working with people with diabetes and to generate inter-professional integration.

The group leaders used a variety of teaching tools, such as flip charts, concept maps, pictures, videos, Power-Point presentations with handouts and role-play scenarios as instruments to convey the programme content. These instruments were meant to encourage participants to observe and reflect on interactions, which was the main strategy used in the programme to consider the participants’ individual attitudes in the delivery of patient care. The approach also encouraged reflections on the professional and personal positions of the participants in their interactions and relationships with others.

Vignette 7-1 outlines a typical session within the programme. Most meetings were similarly staged to create a reflective environment in which participants considered possible interactions between HCPs and patients in self-management education and support. The group leaders in this case also used the metaphor of “tools” to describe the strategies introduced to foster patient engagement so that the participants could understand the core principles and techniques for developing a supportive relationship with the person living with chronic disease. The programme in both settings was delivered by multiple HCPs certified in therapeutic patient education. The

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<sup>6</sup> Original term in French: “les soignants”

programme is one of the axes of the PcD and is intended to introduce the field of therapeutic education to all HCPs, independent of their discipline and specialisation.

#### **Vignette 7-1 Synopsis of typical group meetings in Case C**

On every second Thursday afternoon, the participants met on three separate occasions for 4 hours in one of the meeting rooms. They were welcomed and introduced to each other by the group leaders. In the introductory session, one of the course leaders highlighted the interactive and open nature of the programme: “This is an open and respectful environment in which every opinion can be voiced and will be heard”.

After the participants became acquainted, the course leaders repeated that these courses would provide an introduction “to touch on therapeutic education”. Then they opened the discussion by illustrating some aspects of the different approaches in patient care. One of the experienced group leaders then initiated the first exercise by asking: “What is therapeutic patient education for you? Where do you use it in your context?”

After a few seconds of reflection, the participants described their different understandings. Most spoke about activities related to the care and support of the person with chronic disease<sup>7</sup> – that is, activities that emotionally supported patients in handling their disease. Some referred to the transfer of knowledge, such as informing patients about handling symptoms, or instructing them on a technical aspect, such as taking medications. Two of the participants looked a little bit bewildered, as if they had expected something else. They expressed that they expected to learn about the chronic diseases and never really thought about “how it was to live with a chronic condition”.

The course leaders listened to these different understandings and used them to facilitate an active group discussion regarding the different kinds of interactions and the relationship necessary to “get to know the person behind the disease and not just treat an illness”.

(Field notes, participant observations C-1, C-2)

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<sup>7</sup> Original term in French: “l’accompagnement du patient”

## **7.2 The nature of integration in Case C**

In the context of therapeutic education, the integration of self-management behaviours into daily life is perceived as an individual, lifelong journey for people living with a chronic health issue that is experienced as an intrusive external agent. In this process, they learn over time to live with and treat the conditions and to accept and integrate their disease as part of their identity.

In the context of this case theme, sub-themes were identified that helped HCPs integrate self-management into patients' routine care. These sub-themes related to developing and sharing values in self-management support, assigning meaning to care in support and identifying essential elements in therapeutic relationships. This case encouraged HCPs to develop a shared approach to care delivery.

This ambition was seen as connecting with integration at the patient level by enabling a common approach to self-management education and support. With that approach, the HCPs learned about person-centred care delivery by aligning their own agenda with the patients' agendas, thereby connecting with the patients' learning preferences and styles. In this sense, the nature of integration in Case C included shared values and meanings pertaining to self-management support that incorporated the person-centred care necessary for developing therapeutic relationships that encourage patients to engage in self-management behaviour. An overview of the theme, sub-themes and excerpts of supporting evidence is detailed in Table 7-2.

**Table 7-2 Theme 1: The nature of integration in Case C with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme leader interview data	Programme participant interview data	Observational data	Documentary data
The nature of integration in Case C	Developing and sharing values in self-management support	"We support ... the patient's independence in their self-management ... in each visit. Talking to the patient about what their needs might be at a specific moment, in a specific situation, on a specific day." (C-2-11)	"Because this relationship is based on support, on listening, on allowing the patient to talk, to express their feelings ... rephrasing their thoughts. This is the heart of a supportive relationship." (C-1-22)	The participants exchanged their understandings of TPE with regard to chronic disease. Most expressed that they perceived the relationship between patient and HCP to be more important than the transfer of knowledge. (Field notes, C-1, C-2).	"Raising awareness on therapeutic education in the self-management support of patients with chronic disease." (Programme leaflet)
	Assigning meaning to care in support	"And all of a sudden, the first time I started seeing what it was, I told myself, 'Now, it's not about a sign anymore; it's about the person with that sign or symptom.'" (C-2-12)	"If you start by checking what the patient is concerned about, they'll feel listened to, and they might find their own solutions to the issue." (C-1-17)	The programme deliverer used the term "caregiver" to express the function of HCPs involved in self-management support. Some of the programme receivers adopted the use of this term. (Field notes, C-1, C-2)	"Helping HCPs to strengthen the patient's competencies in self-management of disease and treatment." (Programme leaflet)
	Identifying essential elements in therapeutic relationships	"It's about realising that we are not neutral ... in this relationship. Whether we want it or not, we have an impact. We have something to communicate ... and should use it ... well." (C-2-13)	"You can't manage patients, treat them, take care of them, without establishing a relationship – and one based on trust. Mutual trust builds on respect and when you take your time to listen, even if it's just for a few minutes." (C-1-10)	The participants explored different real work situations by assessing the lived experiences and validating the emotions of patients and HCPs, alternately using role plays, observations and reflections. (Field notes, C-1, C-2)	"To be conscious of the importance of different elements in building up a patient-HCP relationship, such as active listening, verbal and non-verbal communication and the HCP's attitude." (Curriculum outline)

### **7.2.1 Developing and sharing values in self-management support**

The HCPs delivering the programme encouraged participants to reflect on professional habits and the meaning of person-centred care in their daily practice. They raised awareness regarding the importance of common values that were developed and shared between both the interdisciplinary diabetes team members involved in self-management support and people living with chronic disease. A key unifying characteristic within the programme was to build a joint understanding of patient support that involved considering patients as partners in the team (field notes, participant observations C-1, C-2). The programme's intention was to enhance the communication skills of the participants so that they could facilitate a more interactive care experience for patients, built on a supportive relationship to increase the disease comprehension (field notes, participant observations C-1, C-2). This will align the communication practices and styles experienced by patients who interact with different HCPs, thereby creating a common experience in the way HCPs of different disciplines work with them.

Most HCPs positively perceived the idea of building a relationship with patients if it was “based on support, on listening, on allowing them to talk, to express their feelings” (participant interview, C-1-22). The patient support was also related to how important the HCPs perceived self-management to be and how they integrated this supportive role into the way they worked. If they were going to be successful in delivering TPE, they might need to adapt how they perceive their role in delivering self-management support and identify with a different position in this relationship. The programme fostered this by supporting the HCPs in understanding that their core role in self-management support was to accompany the person with chronic disease on their personal journey to help them find ways to live with and adapt to their disease, as explained in these accounts:

We support ... the patient's independence in their self-management ... in each visit. Talking to the patient about what their needs might be at a specific moment, in a specific situation, on a specific day.

(Programme leader interview, C-2-11)

We are here to help them feel better in their lives as much as possible, with our knowledge ... . Quite simply, our job is to support them for a period of time, to give them some advice and suggestions. Then, in the context of their lives, of their beliefs, of their situation, they will accept them or not.

(Programme leader interview, C-2-10)

With that understanding, the HCPs were encouraged to develop a different orientation towards their patients with an emphasis on assisting them in their decision-finding processes, rather than prescribing behaviours in a didactic way. Changing this approach was important to integrate the care delivery model to be more receptive to the patients, such as for example in Case A, which aimed to build patients' personal autonomy in planning their care.

While many HCPs spoke about adopting this new approach, other participants seemed more resistant to it or perceived it as a structured process rather than as a way of being with a patient. This revealed that there may be some limitations to training as the HCP needs to be ready for and receptive to changing his or her practice. The importance of developing and sharing values between HCPs and patients in performing this supportive care was illustrated by an experienced diabetes specialist:

Maybe a way in which you can feel it, or see it, is through values. What values do we share? What values are favoured in the support of a patient? Is the concept of support highlighted in the first place? It's obvious that you are not going to get involved in a work ... to favour a patient's self-management if you think that your role is not to support but to diagnose or prescribe or perform a technical procedure.

(Programme leader interview, C-2-13)



The awareness-raising approach of therapeutic education in this programme intended to foster HCPs' holistic care delivery, which was discussed as being built on supportive relationships with patients. Another factor of person-centred support is using communication skills to elicit patient's prior knowledge and priorities. The importance of co-creating interactions between HCPs and patients is a key factor in this type of care, as expressed in the following account:

If you want, it is also a transfer of skills to give the patient the necessary autonomy to safely – let's say inject insulin – to safely treat his or her disease. And we adapt this to the person's capabilities at that moment. For example, we look at the context to decide together what kind of skills will be prioritised.

(Programme leader interview, C-2-16)

The data suggest that integration in the context of self-management support is influenced by the values developed and shared between the healthcare team and the patient as well as the ways they co-create their interactions. The HCPs may elicit these beliefs by actively listening to what the patient reveals. Therefore, the importance of integrating this kind of care at both individual and professional levels seems to be encouraged by the communication style used in these interactions.

The focus on person-centred self-management to increase personal integration within care delivery was also underlined in the promotion materials of the programme, indicated by the phrase "raising awareness on therapeutic [patient] education in the self-management support of patients with chronic disease" (programme leaflet). This suggests that HCPs may also need support to develop and share values so that they can enable patients to handle their disease and treatment.

### **7.2.2 Assigning meaning to care in support**

In addition to developing and sharing values, the programme intends to further the HCPs' competencies to strengthen patient capabilities in self-management. To underline this supportive role, the programme deliverers used the term "caregiver", illustrating the attention HCPs give to patient needs and individual care. In the course of the group discussions, many of the programme receivers began to voice that their view of the meaning of support was changing from "treating symptoms" to "seeing the person living with these symptoms". They also identified that this shift helped them to understand "the whole person in front of them" (field notes, participant observations C-1 and C-2).

The participants expressed that they changed their approach to opening up the patient discussion at the beginning of their interactions by giving more attention to the patient's most important concern in their current life situation. From that starting point, they followed the patient's agenda as the following interview excerpts from programme participants illustrate:

If you start by checking what the patient is concerned about, they'll feel listened to, and they might find their own solutions to the issue.

(Participant interview, C-1-17)

With therapeutic education, I realised you should start with the patient's concern, and not your own, at the beginning. Maybe it will be something that's got nothing to do with the disease, the pain or any of the things I am currently assessing. Maybe they will actually be upset because of their dog, or something else I don't know about, and that will prevent them from understanding the purpose of our care.

(Participant interview, C-1-14)

The participants began to recognise the importance of building rapport with patients and of giving them time to talk about issues important to them, as expressed in the following accounts from HCPs:

And that relationship is crucial in treating the patient, in understanding when something isn't right. Understanding what they need, actually, that's it. That's what I liked as well, allowing someone this space to express what's going on. What their problem is, not what problem I would prefer to solve.

(Participant interview, C-1-15)

And all of a sudden, the first time I started seeing what it was, I told myself: Now, it's not about a sign any more; it's about the person with that sign or symptom. And that prepares me as a caregiver to be able to approach the other, to see something different than just the scientific side, to have a more holistic view that, maybe, allows me – since it is anyway a supportive relationship somehow, the one that the caregiver builds with the patient – to indeed offer some help not only on a tiny aspect, but on all of the person's needs. That's how I understood therapeutic patient education.

(Programme leader interview, C-2-12)

Assigning meaning to supportive care suggests that HCPs' understanding and acceptance of building relationships with patients is important in delivering person-centred care for people with chronic disease.

### **7.2.3 Identifying essential elements in therapeutic relationships**

When the participants discussed examples from their practice, they used the terms “supportive relationship” and “therapeutic relationship” interdependently to describe the interpersonal interactions in self-management support. Both these terms were based on notions of confidence and esteem (field notes, participant observations C-1 and C-2). In the sessions, the leaders used role plays, with participants being either in the role of a patient, an HCP or an observer in order to recognise the different

positions they take during their interactions. Afterward, they discussed their perceptions of the different roles they observed. A common view among participants was that trust, respect and active listening are important features for constructively working with patients and increasing the likelihood that they adopt positive personal behaviours; as illustrated in the following account:

You can't manage a patient, and treat them, take care of them, without establishing a relationship with them – and one based on trust. Mutual trust builds on respect and when you take your time to listen, even if it's just for a few minutes.

(Participant interview, C-1-10)

Another aspect affecting therapeutic relationships in patient-HCP interactions is the HCP's positions and perceptions. In the case of the HCPs who attended the programme, these were shaped by their former experiences, the conditions within which they delivered this care and the expectations they attached to the interaction. The extent to which they were aware of their own approach to self-management support influenced how they transferred the information to the patients, which some carefully considered in order to motivate the patient, as one of the experienced HCPs conveyed:

It's about realising that we are not neutral ... in this relationship. Whether we want it or not, we have an impact. We have something to communicate ... and should use it [communication] well.

(Programme leader interview, C-2-13)

However, some participants expressed difficulties in adopting the style of communication advocated in the programme, such as using open questions, and tended to revert to closed questions, such as "Did you take your medication as prescribed?" (field notes, participant observations C-1). To counter this tendency, the style of language was reviewed in the group discussions. Following these discussions,

participants began to recognise the value of using open-ended questions to follow the patients' priorities, as exemplified in this account by an HCP recently introduced to TPE:

So, in a way, you can slip in what you want yourself, but you don't lead with that. And this is really something I was taught there [in the programme].

(Participant interview, C-1-16)

Furthermore, this example also demonstrates that the participants perceived their contribution to patient interactions to be more accurate when they connected the information to the patient perspective. As these data suggest, the processes of developing relationships within a reliable and supportive environment may be an important feature for integrating care into self-management support.

### **7.3 The creation of person-centred care**

The theme of person-centred care relates to the different methods that help create the conditions for the delivery of person-centred self-management support. The data were categorised into the sub-themes of using tools to support therapeutic patient education, adopting self-reflection as a concept, and building a team for support.

One of the main aspects of person-centred care is related to the introduction of different tools and their possible benefits in self-management education and support. Another aspect is the use of self-reflection as a concept for building HCPs' consciousness regarding the importance of their own representations of self-management education and support in building therapeutic relationships. While the HCPs develop their understanding of individual care, implementation remains challenging because not all members of the interdisciplinary diabetes team share the same values and professional ethics regarding self-management support. The theme is summarised with the accompanying sub-themes and data sources in Table 7-3.

**Table 7-3 Theme 2: The creation of person-centred integrated care with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme leader interview data	Programme participant interview data	Observational data	Documentary data
The creation of person-centred care	Using tools to support therapeutic patient education	"There are so many steps in therapeutic education. The thing is, a tool is relevant at one particular moment in the patient's journey. To tackle therapeutic education, you need time because you also have to think about yourself." (C-2-10)	"There is this concept of a supporting relationship, which is a huge thing for me. Another one I thought was interesting was picking pictures that could relate to the problem ... and the PRISM [assessment tool] they showed us as well, that was just brilliant." (C-1-14)	The participants discussed different conceptual models and assessment tools to understand their use of self-management support. Most recognised the importance of individually adapting the tools to assess the educational needs. (Field notes C-1, C-2)	"To explore two different tools to support self-management in chronic disease among the tools presented, such as conceptual models, educational diagnosis, photo language, assessment tool PRISM." (Curriculum outline)
	Adopting self-reflection as a concept	"The final goal of this course, if I may say, is to make its participants want to reflect on the relationship." (C-2-14)	"It [self-reflection] is ... something I really like in the therapeutic education. I'm someone who likes finding solutions, a lot of caregivers are like that, aren't they? This ... helped me to know myself better." (C-1-15)	The participants chose from 40 photos to represent their definition of chronic disease and discussed their vision for interdisciplinary self-management support. (Field notes C-1, C-2)	"To reflect on the individual meaning of chronic disease and discuss the place of chronic disease in the patient's life and the care relationship." (Curriculum outline)
	Building a team for support	"Same values in the ethics of a team, in a philosophy of care ... . Wanting the patient to be supported and making the effort to delegate or surrounding yourself with other people who make up for the skills that you don't have." (C-2-13)	"It would be good to train the whole team in therapeutic education to continue this kind of support in the delivery of care". (C-1-17)	The participants reflected on the different HCPs' representations in self-management support and discussed how that challenged working in interdisciplinary teams. (Field notes C-1, C-2)	"Getting acquainted with different HCPs from the region." (Programme leaflet)

### **7.3.1 Using tools to support therapeutic patient education**

A key element of the programme was learning how to use the tools for delivering TPE. The terms therapeutic patient education and therapeutic education were used interchangeably during the programme. To help participants see the value of the tools used in TPE, the programme leaders contrasted the traditional medical model of care with the approaches and tools used in TPE, many of which were novel to the participants.

The participants were made aware of the different communication styles and types of questions used in these models through role plays and group discussion to raise their competencies “to elicit the support needs”<sup>8</sup> of people with chronic disease. This enabled them to generate a better understanding of the kinds of experience created by the different types of communication (field notes, participant observations C-1, C-2).

Some of the selected tools assessed the illness representations and level of distress, such as the PRISM (Pictorial Representation of Illness and Self Measure), which is an instrument used to assess patients’ self-perceived disease burden (Buchi & Sensky 1999), as illustrated in the following account expressed by a participant with a few years of professional experience:

There is this concept of a supporting relationship, which is a huge thing for me. Another one I thought was interesting was picking pictures that could be related to the problem ... and the PRISM [assessment tool] they showed us as well, that was just brilliant.

(Participant interview, C-1-14)

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<sup>8</sup> Original term in French: “diagnostic éducatif”

As illustrated, some of the participants seemed to value the concrete tools they could use in their professional practice because they provide tangible techniques that support them in delivering TPE in their practice. It is interesting to note that several programme participants focused on these tools, whereas the programme leaders emphasised that the tools were only instruments for understanding a patient's needs at a specific moment and, as such, should be integrated into the overall strategy of patient support. They cautioned participants not to use the tools in isolation because they need to be integrated with the overall principles of TPE. For example, two programme leaders stated the following:

It's not only about approaching a patient and telling them: "Now I have a great tool – here it is ...". [It is about] asking questions to better understand, finding out the patient's progress in their willingness to change, and then the motivation assessment, the contracts, the follow-ups ... these are very time-consuming things.

(Programme leader interview, C-2-11)

There are so many steps in therapeutic education. The thing is, a tool is relevant at one particular moment in the patient's journey. To tackle therapeutic education, you need time because you also have to think about yourself.

(Programme leader interview, C-2-10)

As the data indicated, when integrated into the overall approach of TPE, participants generally perceived the tools used in TPE as beneficial and useful for working with patients in a co-productive way.

### **7.3.2 Adopting self-reflection as a concept**

The programme content encouraged the HCPs to consider their own positions in delivering self-management support. In this sense, self-reflection was implicit in the



HCPs' participation in the programme because they were seeking to change their approaches to patient interactions by developing their skills in TPE. While the participants did not directly voice a desire to provide a more integrated care approach, they recognised that the medical model they followed did not adequately engage patients in self-management. Hence, by participating in the programme, the HCPs made an initial step towards reflecting on their practice and working with patients in a new way that would connect to patients' views, needs, priorities and experiences in order to build a relationship. An experienced course leader explained the purpose of reflective practice:

The final goal of this course, if I may say, is to make its participants want to reflect on the relationship.

(Programme leader interview, C-2-14)

Some HCPs recognised that their direct influence was small as most of the day-to-day decisions were taken by the person living with the condition, as expressed in the following excerpt:

To make them [the participants] be aware that they are reflecting on it [relationship], and to make us think, "In my daily job, regardless of my role or profession, I have a small impact, or influence in the relationship that the person in front of me has with their disease".

(Programme leader interview, C-2-13)

This shows that when the HCPs adopted a more reflective approach, they perceived themselves to be primarily in a facilitating role with regard to self-management support, which was also influenced by their own disease representations. In an exercise for visualising different meanings and interpretations of chronic disease, the participants chose two photos from more than 40 illustrations to visually represent how they viewed a chronic condition. Then, in group discussion, they related their

choice to different relationships, such as “for me, it represents a journey with many turns to go with the patient; that’s why I have chosen the picture with this narrow curvy road” or “I have chosen this crossing as it represents the choices patients can make” or “for me, it represents constraints for patients that’s why I have chosen this stop light” (field notes, participant observations C-1, C-2). This exercise supported the participants in reflecting on their representations of chronic disease and in considering the possible impact their conceptualisation might have on building a supportive relationship with patients. Another reflection raised was that the participant HCPs struggled in the past to change their behaviour and defaulted back to trying to fix patients’ problems rather than working in partnership with them. In general, HCPs prefer to take a curing and leading role in their interactions, as voiced by both programme leaders and participants in the following accounts:

It [self-reflection] is also something I really like in the therapeutic education – I’m someone who likes finding solutions, a lot of caregivers [HCPs] are like that, aren’t they? This [programme] really helped me to know myself better.

(Participant interview, C-1-15)

And I think the caregiver [HCP] still really wants to cure, to save people.

(Programme leader interview, C-2-10)

These data suggest that the HCPs’ expectations related to “doing something” challenge the way person-centred approaches are integrated into care. Adopting reflection as a concept supported the HCPs in considering their own positions and representations in relationship building.

### **7.3.3 Building a team for support**

A key factor expressed in the participants’ accounts was related to building a common approach to self-management support across a healthcare team. The programme

addressed many different kinds of HCPs independent of their profession, and so helped them to become acquainted with each other and to consider how acceptable this care approach was for them as a team. In group discussion, the participants considered different ways to use the TPE approach in a multidisciplinary team. Although most participants showed interest in using more collaborative approaches in patient education, some of them conveyed concern about receiving “little support from their work environment” through “irregular or insufficient numbers of team meetings”. They perceived that precisely having a “regular meeting with other team members” would help them to overcome hindrances. This desire was expressed as “it is important that we pass the information to each other so that we can work together” (field notes, participant observations C-1, C-2). Knowing the other team members and recognising their specific competencies influenced the HCPs’ collaboration. Teamwork was also fostered by the way they valued each other and gave attention to communication, as voiced in this account:

Communication does not come by itself ... we have to work on it. When several people with different professional backgrounds come together, we need to perceive each of them as competent and important besides their professional role and ... this already sets the tone for teamwork.

(Participant interview, C-1-10)

The examples above suggest that HCPs should regularly reflect on their communication style and consider their approaches to information transfer. Some of the participants reflected on their collaboration and, as a result, adapted their thinking regarding a team approach to patient care, as expressed by the following:

We must also question ourselves in a multidisciplinary team ... our profession evolves, and we need to ask ourselves how we can improve the way we think ... the way we care as a team.

(Participant interview, C-1-14)

This reflection may indicate that some of the participants internalised a collaborative mindset, which may be important in translating the person-centred approach into their routine practice. However, the team approach to supportive care was more challenging for some participants who spoke about a work context that was not willing to accommodate a change in the care delivery model. Hence, the extent to which person-centred self-management support can be integrated into routine care may be limited by contextual factors. This led one participant to suggest that the programme should target the whole diabetes team:

It would be good to train the whole team in therapeutic education to continue this kind of support in the delivery of care ... we could try together to find a way to train more people in our institution as there is the saying “the cobbler’s children are the worst shod.”

(Participant interview, C-1-17)

The data suggest that although the integration of TPE into the team approach to patient care was perceived as beneficial, it had not yet been fully accomplished and still required further efforts for training the whole team about the different approaches used in self-management support. Building a team for providing person-centred integrated self-management support demands an additional effort by all HCPs to reflect on their values, strengths and weaknesses in the delivery of care:

Same values in the ethics of a team, in a philosophy of care ... Wanting the patient to be supported and making the effort to delegate or surrounding yourself with other people who make up for the skills that you don’t have.

(Programme leader interview, C-2-13)

The data also demonstrate that the programme supported the generation of inter-disciplinary team integration by encouraging the building of a patient support team working in a network with similar values.

#### **7.4 The competing paradigms of care**

The theme of competing paradigms of care captures some of the challenges in self-management education delivery and reveals some interesting findings regarding the care models implemented in this context. The following aspects were identified in the data: recognising complexity in interactions of support, understanding prevailing mindsets and congruity of the culture of care.

One of the main aspects of competing paradigms of care is related to recognising complex interactions that may emerge at multiple levels and from different perspectives of self-management education. The complexity of addressing patients' biological, psychological, educational and social needs requires HCPs to be motivated and trained to attend to these challenges.

Another aspect of competing paradigms of care pertains to the prevailing mindsets of the participant HCPs who followed a specified care concept in self-management education delivery. Their narratives help to identify dominant care approaches present in their interactions.

However, integrating person-centred self-management education and support in a sustainable manner across different points of delivery requires that HCPs accept and congruently deliver the new approach, which is another important aspect that relates to the wider integration of the culture of care in this context.

In this sense, the implementation of self-management education in routine care addresses the emerging manifold challenges in interactions and relationships with patients. Such relationships are shaped by the care approach of HCPs and the team members' response to care delivery. An overview of the theme, sub-themes and data excerpts is detailed below in Table 7-4.

**Table 7-4 Theme 3: The competing paradigms of care with the sub-themes and excerpts of the different data sources**

Theme	Sub-themes	Excerpts of data sources:			
		Programme leader interview data	Programme participant interview data	Observational data	Documentary data
The competing paradigms of care	Recognising complexity in interactions of support	"Realising how complex the relationship between a caregiver and a patient is. That means going beyond the biological aspects of the disease management to include other notions linked to psychological, social, behavioural and educational aspects." (C-2-14)	"First thing you need is will. The will to live something more meaningful with that person ... . So precisely, you need motivation, awareness of the whole relationship, as well as knowledge. And yes, you need to want to get further training." (C-1-15)	The participants used case reviews with an interview guide representing different care models. They discussed the different challenges of multiple interaction scenarios in self-management support, addressing the various aspects of this care. (Field notes C-1, C-2)	"To introduce the development in the care of people with chronic disease: from the biomedical model to a bio-psycho-educational-social model." (Curriculum outline)
	Understanding prevailing mindsets	"It is this specific element – caregivers considering patients as partners. I bring some elements, the patient brings their own, and together, we build something ... and a different relationship is born." (C-2-13)	"It [may be] a vicious circle – there's always an action and a reaction – grievances, communication issues – and it will only be getting worse. I think that when you can immediately apply the concept of a therapeutic education, you start off on the right foot". (C-1-17)	The participants observed two video sequences with different approaches to self-management followed by an interactive discussion of these concepts, expressing their perceptions of the HCPs' attitude and patients' reaction in light of different communication styles. (Field notes C-1, C-2)	"Presenting examples of conceptual models and their practice." (Programme leaflet)
	Congruity of the culture of care	"Because the role of the HCP as someone who knows – that's rather reassuring compared to the role of a caregiver, which is much less reassuring because you are less of an authority figure, you allow the other to be at your level." (C-2-12)	"I think it's not something everyone can do ... because it involves maybe discovering your own shortcomings, and some people ... honest mistake, maybe, but some people may have working habits that are perhaps not the best adapted." (C-1-15)	The participants reflected in pairs on different situations using conceptual maps to illustrate the barriers and facilitators for their specific context. Some of the challenges were discussed with the whole group, such as team perception of care. (Field notes C-1, C-2)	"To identify the prevalent representations of the caregiver and discuss how HCPs might handle barriers and facilitators in their context to better support the patient self-management." (Curriculum outline)

#### **7.4.1 Recognising complexity in interactions of support**

An area of complexity highlighted in the programme was how to respond to the different needs of patients as indicated in the account of one of the experienced diabetologists:

Realising how complex the relationship between a caregiver and a patient is. That means going beyond the biological aspects of the disease management to include other notions linked to psychological, social, behavioural and educational aspects ... . Unfortunately, these are often ignored in the management of a patient with a chronic disease”.

(Programme leader interview, C-2-14)

This complexity implies that although self-management support is offered in the care delivery, the HCPs are not always aware of how to engage in a holistic care approach. Thus, they might compromise with a tendency to privilege the clinical agenda.

By discussing their own cases, the HCPs identified compensating strategies to address this challenge. For example, as they discussed different ways to encourage regular insulin injection, they proposed that “a less technical instruction” would “improve the patient’s engagement” to “find an individual solution within their own possibilities” leading to “better acceptance of actually injecting the insulin” (field notes, participant observations C-1).

The participants also recognised that they needed to develop their own personal motivation to change how they interacted with patients:

First thing you need is will. The will to live something more meaningful with that person ... . So precisely, you need motivation, awareness of the whole relationship, as well as knowledge. And yes, you need to want to get further training ... some of us are very good with the technical aspect, but I think that’s the thing, you need more than technique.

(Participant interview, C-1-15)

After programme participation, some HCPs voiced concern about their abilities and the time resources needed to take care of these multiple demands in self-management support, as expressed by one of the recently qualified participants: “I’m not sure if I have the time and the skill to do that [self-management support]” (participant interview, C-1-13). Thus, some HCPs recognised the complexity of the interactions required for self-management support as a result of their participation in the programme, indicating that their understanding of this kind of care changed.

The data suggest that comprehensive self-management support is challenging and might not be effectively integrated into the care delivery experienced by patients. Furthermore, this lack of integration could also be influenced by the different understandings of care prevalent in multidisciplinary teams. Therefore, overlooking the complexity of the interactions required for effective self-management support might lead to suboptimal care delivery and prevent such support from being integrated into routine patient care.

#### **7.4.2 Understanding prevailing mindsets**

The prevailing mindsets of HCPs relate to the cognitive processes that may represent professional behaviour activated in response to an identified work task. The participants expressed that their ways of responding to these tasks were a result of their previous learning, the existence of preconceived ideas and their preoccupation with their own agenda. The data identified, that these elements influenced their understanding of self-management education and represented concepts on how they approached patient care. Participants recognised that their interactions were more person-centred when they used the therapeutic education model as expressed in the following account:



It [may be] a vicious circle – there’s always an action and a reaction – grievances, communication issues – and it will only be getting worse. I think that when you can immediately apply the concept of a therapeutic education, you start off on the right foot.

(Participant interview, C-1-17)

However, some HCPs expressed different priorities that guided their interactions, and “sometimes they answered their own questions related to what they wanted to hear” (field notes, participant observations C-1, C-2). This may suggest that some HCPs were preoccupied with their own motives and less responsive to the patient’s needs, although they believed to use a person-centred approach to patient care. The participants identified the concept used in TPE to help them in considering their own mindsets prevailing in interactions with patients. To support the HCPs in their learning processes, the leaders facilitated an exercise that presented some communication strategies. The group leaders introduced the exercise by comparing two video sequences in which two HCPs announced the same diagnosis and treatment using different communication strategies. In the first sequence (5 minutes, 10 seconds), the HCP adopted a medical approach focusing on biological results, symptoms and treatments, using mostly informative language and closed questions; in the second (7 minutes, 58 seconds) TPE was exemplified to inform the patient in a person-centred approach reflecting the patient’s individual context. Although the second sequence was slightly longer, the participants perceived it to better support the patient’s needs. In that video sequence the HCP also had been accustomed to basing the interactions on the diagnosis, but the communication was indirectly led by giving the patient the opportunity to express emotions and immediate concerns (field notes, participant observations C-1, C-2).

It was observed that the participants also started to use the term “caregiver” in the participant observations when they referred to their perceived role (field notes,

participant observations C-1, C-2). This suggests that the participants took on a more supportive role with regard to how they delivered self-management support; some recognised that they had a different position when using TPE in care delivery, as expressed in one of the experienced programme deliverers' narratives:

It is this specific element – caregivers considering patients as partners. I bring some elements, the patient brings their own, and together, we build something ... and a different relationship is born.

(Programme leader interview, C-2-13)

In contrast to the traditional role of HCPs, the participating HCPs perceived the notion of co-creating interactions to be a key mechanism for supporting person-centred self-management. The data suggested that the additional training in TPE supported HCPs to reflect on how their own prevailing mindsets may influence their interactions with patients and other HCPs. In doing so, they expressed that partnership with patients and collaborative inter-professional work with other HCPs may enhance interactions between all parties involved in self-management education and support. Therefore, the integration of a person-centred care approach into HCPs mindsets and the overall culture of care may enhance and sustain patients' experience with supportive self-management education in routine care.

### **7.4.3 Congruity of the culture of care**

Although the understanding of self-management support was described differently by individual HCPs, most participants stressed that the delivery of self-management support should be connected to a person-centred culture of care practice. While most perceived self-management education and support as beneficial and were interested in continuing with this care model, some experienced programme leaders voiced concern about the implementation of self-management support in practice. They

feared that HCPs would revert into old patterns when the care approach was not incorporated into the care delivery team, as expressed in the following accounts:

I don't know how you have perceived your work after this programme, but I, each time I return after the courses ... it is like taking a cold shower ... I work in a group where most still use a different approach.

(Programme leader interview, C-2-10)

Changing professional practice takes time and is not always supported by the team.

(Participant interview, C-1-20)

These examples indicate that some participants had difficulties using the TPE model in practice because their work environment did not encourage the implementation of the new approach. Similarly, some perceived themselves not to be in a position to influence care practice, at least not in the short term.

The programme supported the HCPs in considering different factors that influence the integration of self-management support by providing an opportunity for them to discuss the prevailing representations of the HCPs in their context. In pairs, they discussed different scenarios and designed conceptual maps illustrating the factors that influenced those experiences. Their accounts identified that the way how the members of an interdisciplinary diabetes team congruently delivered the person-centred care approach was a key mechanism relating to the “team perception of care and the delivery of self-management support” (field notes, participant observations C-1, C-2).

Changing the approach to care delivery may also provoke a degree of resistance in some HCPs who may not be willing or skilled enough to evaluate their own behaviour, as expressed in the following account:

I think it's not something everyone can do. At any rate, it's not something everyone wants to do because it involves maybe discovering your own shortcomings, and some people ... honest mistake, maybe, but some people might have working habits that are perhaps not the best adapted.

(Participant interview, C-1-15)

The programme addressed these challenges by encouraging the HCPs to reflect on their previously learnt positions, thus challenging their preconceived ideas. As a result, the HCPs considered how to adapt their function and to facilitate self-management support by transferring skills, as expressed in the following accounts:

Because the role of the healthcare professional as someone who knows – that's rather reassuring compared to the role of a caregiver, which is much less reassuring, because you are less of an authority figure, you allow the other to be at your level.

(Programme leader interview, C-2-12)

A phrase that stuck with me ... which I liked a lot was “deconstruct to reconstruct”. It's about breaking the obstacles, deconstructing the preconceived ideas, changing the way we've always thought.

(Participant interview, C-1-15)

Therapeutic education changes the perspective on the caregiver's role. It means it changes their status, and that is difficult in therapeutic education – putting yourself in a position that differs from the one that you've been taught.

(Programme leader interview, C-2-11)

In this sense, reflecting on congruity of care between team members was an essential mechanism of the programme for encouraging participants to re-evaluate their care delivery of self-management education and support and thus to enhance the patient experience.

## **7.5 Summary**

The data from Case C illustrate the importance and challenges of HCPs delivering TPE in their practice. This not only involves equipping HCPs with the skills to do so but also emphasises the need to adapt their personal frame of professional practice, from a clinician-centred to a person-centred approach. The data also reveal the importance of the context of care and ensuring that it accommodates the TPE approach. Thus, in addition to helping HCPs acquire skills, it is also necessary to address how they view patients and prioritise the care agenda accordingly. The findings also emphasise that if the overall philosophy of a programme is going to be operationalised, then that philosophy needs to be integrated into and adopted by the wider care system. Overall, while some participants found it challenging to acquire the capacity (including communication skills) needed to enable patients to engage in their own care process, most perceived these skills as valuable for supporting patients in integrating self-management practices into their personal care routines. In this sense, Case C encouraged integration by developing shared values and creating the conditions for delivering person-centred integrated self-management education across settings. Case C also helped HCPs in recognising the issues that may impede them from implementing the TPE model in routine care.

## **Chapter 8 Cross-case analysis and synthesis**

In this final results chapter, a synthesis of the findings from the individual cases is presented in order to provide a collective interpretation of the data. The synthesis constructs an overarching theoretical perspective regarding the nature of integration in self-management education at patient, HCPs and system levels with mechanisms and components of integration identified from the cases. The chapter presents the following points:

- The nature of integration at personal, patient-to-patient, HCP-to-patient and HCP-to-system levels that describes the experiences and perceptions of integration by programme participants (receivers and deliverers) in the context of person-centred self-management education.
- Mechanisms and components of integration observed in the different cases that influence integration within the contexts of self-management behaviour and support, thus expanding the components of integration identified from the synthesis of previous studies, as presented in Chapter 2.
- Synthesis of the primary data from the individual cases in the context of interactions between levels, mechanisms and components of integration (see Figure 8-1), as well as the theoretical model that integrates the identified mechanisms and components into the model of person-centred integrated self-management education (see Figure 8-2).

The synthesis is based on cross-case connectivity – that is, on an exploration of both the common and unique characteristics of integration identified in the individual cases. Such cross-case interpretation captures both the shared and distinct elements between the cases in order to identify potential mechanisms and components for developing future self-management education and support programmes.

## **8.1 The nature of integration**

The nature of integration in relation to self-management education has been identified as a multifaceted construct with different operational components and mechanisms that either directly or indirectly play a role in how patients are supported in adopting self-care activities and develop self-management behaviours. Direct forms of integration relate to the extent to which programmes enable patients to integrate their self-management behaviours into their life routines as well as the extent to which such programmes provide support and resources for them to nurture these routines. Indirect forms of integration relate more to the context of integration and how it is defined and supported by a programme. This indirect element includes considering how care is organised and the training required for HCPs – namely, that a care system co-ordinates its efforts with a high level of continuity in self-management support. Across the cases of this study, integration was seen to operate at multiple levels. This subsection describes the different levels of integration identified at the following levels:

- personal integration – the impact of the programme on how people with T2DM experience their condition;
- patient-to-patient integration – programme participants sharing their experiences to inform individual and group education;
- HCP-to-patient integration – shifting HCPs' paradigm of care towards person-centred care;
- HCPs-to-care-system integration – HCPs implementing person-centred self-management education.

These different levels of integration were observed in the cases to various extents, reflecting the context and focus of the interactions within each programme. It was possible, however, to observe some unifying mechanisms and components that

informed the expression of integration. The different levels of integration and corresponding key mechanisms and components are explicated below.

### **8.1.1 Personal integration**

This level of integration relates to how patients identified with T2DM, their health condition and disease treatment – whether as something that is part of themselves and incorporated into their routines or as something external to themselves. Personal integration was related to participants' self-management practices, such as whether they assimilated the routines of self-management into their lives or whether these were avoided or seen as annoying tasks. Personal integration was also evident at an emotional level, in respect of how they felt themselves as a person living with diabetes and their acceptance of it. Within the programmes focusing on the patient (cases A and B), it was evident that some participants began to identify more with their disease. Promoting such personal integration was an important feature observed in the overall ethos of the programmes.

This was evident in the way patients learnt on their own (through reflection) and from peer experiences that enabled them to develop new insights into how they constructed and oriented their diabetes within their lives. Another strategy for personal integration revolved around group-based activities in a safe environment, which helped patients build self-confidence and reduce inhibition to exercise or share experiences with others. The programme then encouraged them to identify how they could build healthy behaviour into their life routines, integrating their disease management into their personal world.

An important feature of both patient-focused programmes in relation to personal integration was encouraging the participants to consider the benefits of adopting self-management practices. The programmes communicated the potential for them to



improve their sense of well-being and personal health and encouraged them to leave behind some of the negative orientations they had held towards themselves and towards the demands of their condition.

The strategies for supporting HCPs in facilitating patients' learning processes (Case C) indirectly encouraged personal integration by providing the HCPs with the skills to enable patients develop self-management behaviour. For this reason, personal integration was expressed both as an outcome in the sense of feeling more able to integrate diabetes in one's life and as a process in the sense of feeling one's experience of the programme continue in the general care experiences and interactions with HCPs who offer support for integrating diabetes into one's life. These processes included the learning experiences (shared learning with and from peers) and connectivity with other processes, such as the ethos of the programme, training of HCPs with advanced skills and approaches to enable patients to attend to their self-management.

The findings from the cases illustrate that personal integration, expressed as an outcome, was not a fixed phenomenon; instead, the participants came to the programme with varying levels of personal disease integration and also exhibited varying degrees at the end of the programme. While most improved in integrating diabetes into their lives, it was less so for others indicating that not all benefitted the same way from programme participation.

### **8.1.2 Patient-to-patient integration**

Patient-to-patient integration refers to how patients shared their lived experiences and perspectives of living with chronic conditions within the group education activities. This level of integration has a number of functional components. For example, it encourages personal and shared reflection, allows a degree of stabilisation because

participants can identify with others and constructs new behavioural options for participants through group discourse.

Through the patients' exposure to group discussion, they became familiar with others who described similar issues. Such exchanges typically included conversations about symptoms and emotional responses to concerns about living with chronic conditions, thus enabling participants to share strategies to enhance or maintain their well-being and prioritise different life demands. The group dynamics influenced patients' engagement in discussion and physical activity training groups; some even developed a kind of bonding with their peers. Moreover, the perceived social support was a motivating factor for most participants to continue engaging in the activities because the prospect of regularly meeting peers was encouraging. However, a few felt that the demographic composition of the group did not meet their expectations – primarily because the group did not respond to their needs. While most of the HCPs perceived peer support as a valuable resource, some also raised concerns about their own skills and capacity to facilitate such support within their care contexts.

Therefore, the facilitation of patient-to-patient integration through social support within the programmes was identified as a key form of integration and an important mechanism for promoting positive self-management behaviours as well as personal integration. Social support was also a key characteristic of this form of integration because it enabled patients to develop a collective understanding in response to common concerns and to share solutions about how to live with their health problems.

### **8.1.3 Healthcare-professional-to-patient integration**

Healthcare-professional-to-patient integration was primarily expressed in how the peer and professional educators interacted in the group sessions. Such interactions were shaped by the HCPs' understanding of self-management, and they

subsequently adapted their behaviour in their educational interactions. The integration of different viewpoints brought the ethos of the HCPs and peer facilitators (people living with chronic disease) closer together. The data illustrated that HCPs moved from a hierarchical relationship, where patients were in a dependent role, towards a state where both could reciprocally learn from a different story. The HCPs could learn how it was to live with the disease, and the patients could learn how to handle the disease and to participate in a healthcare team.

The active involvement of peer educators brought patients' agendas to the fore in the learning experience, thereby encouraging the participants to be more actively engaged in the learning. Indeed, the presence of peer educators promoted the patient voice, giving it equal status to the expert professional voice. The integration of those two voices meant that the participants could observe why there might be some discrepancy between the patient and professional agendas. It also allowed them to consider how they might reflect on and navigate that discrepancy. In that sense, the patients received a set of transferable skills to enhance their care experience with their general practitioner or any other member of their healthcare team when they left the programme. There was no explicit peer educator observed in Case C, although one of the features in the HCPs' skills training was to enable HCPs to understand the potential dissonance between their agenda and that of the patient. Hence, they had to learn that the voice of the patient needed to be incorporated into a mutual dialogue resulting in agreed upon care objectives, rather than HCPs simply prescribing behaviours.

Therefore, HCP-to-patient integration may emphasise the importance of negotiating and aligning both agendas as a key mechanism of integration in order to foster co-created interactions that promote patients' motivation, engagement and ability to succeed in their self-management objectives.

The second aspect of HCP-to-patient integration relates to how the HCPs changed their approach to interacting in medical encounters by shifting their paradigm of care. In addition to the previous level of integration, this level encouraged the HCPs to shift their professional identity and to adopt a more collaborative way of working with the patient to better attend to the patient agenda. In this sense, some HCPs were able to assimilate the patients' perspectives within the self-management support they provided by being more mindful of patients' agendas alongside their own.

This change in the relationship between the HCP participants and the patient participants also encouraged a more collaborative dialogue – for example, developing shared action plans for more acceptance and implementation of the treatment options. While most people with T2DM conveyed that they felt positively about the integration of their personal experience, which gave them an active role in personally influencing their condition, a few expected more explicit guidance from the facilitators. These participants may not have felt ready to take on more responsibilities, or they may simply have preferred to be more directly advised on what to do.

In general, the HCPs' creation of an environment that encouraged participants to support each other and to connect with peers with similar issues was instrumental in the group deciding to continue to meet and exercise once the programme had concluded. In this sense, the HCPs' effort to integrate the programme content with the patients' own frame of ability and life context as well as with a group of peers may result in these participants being more able to sustain their positive health behaviours.

The programme concept of encouraging HCPs to reflect on their skills stimulated them to consider their own role in interactions between care deliverers and recipients. While Case C included no overt observation of HCPs interacting with people with T2DM, it was the purpose of the skills training programme to prepare HCPs to better deliver person-centred self-management support. After going through that training, the HCPs

may be enabled to better support patients in integrating their condition into their lives. During the skills training programme, the HCPs were observed to use a different kind of diction when they moved from describing their profession and specialisation to defining their role as caregiver. This might be an indication of their perception of becoming a different kind of HCP, emphasising their function in the patient care processes rather than their profession. Although, it was also observed that some HCPs found this approach challenging either because of their own underlying beliefs about their professional identity or because of organisational constraints within their work area.

#### **8.1.4 Healthcare-professional-to-system integration**

This level relates to the extent to which HCPs developed or adapted their care delivery systems to support patients in becoming more involved in their own care. However, the data also suggest that there may be some limitation to the extent to which HCPs could or did adapt their delivery systems to support a more collaborative approach to care delivery. The data further suggest that the way patients experience care delivery may be important in shaping their self-management behaviours. Hence, this level of integration relates to a number of factors that mediate the relationship between self-management education and support in patients' experience of care delivery and their interactions with HCPs in routine care.

The cases illustrate how the HCPs operationalised each programme within their care system. This operationalisation was influenced by the degree to which the HCPs' outlook and the programme ethos matched each other because this congruency or lack thereof was transported into the care delivery system. The paradigm of care observed in the cases enabled patients to actively participate in the treatment and encouraged them to share their lived experience because such sharing was given the same importance as the professionals' expertise. The programme of Case C aimed

to equip the HCP participants with the skills and underlying approach to allow them to work with patients in a collaborative way. For example, the training units using reflective practice in building supportive relationships and open questions in the consultation approach were exemplified in Chapter 7. Moreover, Chapter 5 showed how the HCPs applied these approaches to encourage patients to actively participate in co-creating their care objectives. In this sense, the integration of the paradigm of care into the way the HCPs delivered the programme within their care system related to whether they accepted and congruently delivered the ethos of the programme. This was evident in the data, which identified congruity with the paradigm of care as a key factor pertaining to system-level integration. In that sense, the extent to which the HCPs embraced the paradigm or ethos of the programme and adopted that concept to adapt the way they worked with a person with T2DM influenced the programme delivery.

An important feature of this integration was the availability of resources in the ongoing care system that would help the HCPs support the learning patients had been exposed to in the programme. For example, the patients received separate information on how and where to continue their training using different communal resources, not restricting the support options to the programme itself. Another approach used was encouraging them to continue their workouts in peer follow-up programmes. In this sense, the cases offered choices to the patients to better maintain their training according to their own pace and preference. The continuous support options were intended to help patients to better integrate self-management behaviour into their routines over time and to continue this process according to their needs, independent of any one programme or HCP.

By engaging in reflection, the HCPs became more aware of the importance of their relationship with patients and other HCPs – namely, that the communication used in

these interactions could either facilitate or hinder patients' self-management practice and disease integration. The interactions between HCPs were extended to the whole multidisciplinary team as the participants of Case C were encouraged to build a network of care in order to develop a shared understanding of self-management support. However, while most of the HCPs voiced an interest in this kind of collaborative care, some raised concerns about how they could actually implement such delivery at their place of work. Some of these participants described working in strict hierarchies, and they perceived limited possibilities for introducing new models of working with patients. While there were no observations of direct interaction, it is interesting to note that these HCPs viewed their colleagues' resistance to change as one of the biggest challenges to implementing a more person-centred form of self-management support. In that sense, Case C also permitted the HCPs to consider and perhaps develop better co-working behaviours within the conditions of their contexts.

In exchanges within the healthcare team, the HCPs expressed their desire to move from a hierarchical understanding of working together towards more collaboration. This transformational process was illustrated by the changed perception of their professional identity, with the participants describing themselves as caregivers and part of a more homogenised group of HCPs delivering self-management education and support. Although some of the participants raised concerns about the transferability of this reframing to their workplaces, most were motivated to try to implement the principles of person-centred self-management support in their practice. In that sense, the congruity of the paradigm of care espoused by the programme was influential in encouraging the HCPs to adopt the model and in the extent to which the overall ethos of the programme could be integrated into the delivery of routine care.

To summarise the findings of the synthesis, it is possible to identify from the data some unifying characteristics describing the integration of self-management

education and to extract some active mechanisms, which seem to facilitate the way integration is expressed within and across the different levels. The mechanisms are expanded more fully in the section below.

## **8.2 Mechanisms of integration**

In this section, the different mechanisms that have the potential to enhance the integration of self-management education and support in routine care are explicated in more detail. The mechanisms relate to the processes that potentially facilitate or hinder integration. Consideration is given to how these mechanisms operated across the cases studied in order to explain the unifying mechanisms that inform the expression of integration. The identified key mechanisms are detailed below.

### **8.2.1 Identification with condition and activity**

This mechanism is based on the relationship between participants' identification with their condition and their active participation in their self-management and healthcare interactions. This involvement was identified in the data to have the potential to encourage the process of individual disease integration. The development of this integration was in part driven by allowing the participants to share their experiences with both their peers and HCPs. Thus, more equal contributions in these exchanges have the potential to create mutual learning for all involved in self-management education and support. The expected gain through this reciprocal learning is that it mediates more active patient participation and develops inter-professional working and supportive care delivered across the pathway of patient care. If care delivery improves, people with T2DM may experience more supportive care, which in turn may encourage their personal disease integration. Therefore, programme concepts that incorporate elements of active participation and experience sharing may stimulate



participants to identify more with their health condition and activity, which, in turn, may help them to integrate self-management practices into their daily routines.

### **8.2.2 Experience of social support**

Social support was observed to be an enabling mechanism in the cases, which was mediated through the use of peer support to encourage the sharing of lived experiences among participants. This exchange process enabled participants to compare their own experiences to those of others and to experience shared learning regarding how to deal with the challenges that come with managing their disease. As a result of such learning, they may amend their own behaviours or resolve potential barriers to their active participation in self-management practice.

Most participants experienced social support as being helpful in their disease integration processes, although the extent of possible benefits was influenced by the composition of the group within which participants were interacting. Furthermore, they expressed that exchanges with peers supported them emotionally and extended the advice they received from HCPs. In that sense, the integration of social support is complementary to self-management education, which predominantly gives participants skills and knowledge about disease and treatment. In addition, some participants expressed that they developed a relationship of support with their peers. This bonding furthered their motivation to interact and to consider other ways to participate further in their treatment strategies.

Therefore, the integration of social support may be a core ingredient in encouraging individuals to identify with their disease as well as to engage in self-management behaviour.

### **8.2.3 Co-creation of interaction**

This section describes some of the personal and organisational barriers and facilitators to implementing the programme concept of enhancing self-management in practice. One of the mechanisms identified in the data was the way in which the cases integrated the different views of self-management education and support to better connect the expectations and needs of both the HCPs and patients in their interactions. In this sense, considering the different perspectives and interests in such interactions was a crucial step. This is because HCPs' commitment to building an environment that supports the co-creation of interactions is a key driver for the delivery of self-management education and support, where patients are enabled to actively participate and voice their needs and preferences.

The reflective practice in Case C supported the HCPs in adjusting their behaviours to allow patients to become more central in the dialogue around planning their care. The extent the programme training led to changes in care delivery may be mediated by the care system context because the existing processes and structures may either advance or limit the potential for HCPs to enact person-centred care models.

### **8.2.4 Congruity of care paradigm**

The extent to which HCPs felt equipped to enact the programme ethos in their care was mediated by the prevailing care paradigm in their area of practice. When the care paradigm adheres more to the biomedical model, it may be challenging to enact a person-centred approach. As a result, integration of the programme in relation to the ongoing care experiences of patients may potentially be impeded. Hence, the extent to which the HCPs could integrate the person-centred care approach into routine care delivery is influenced by the extent to which the culture of care established in their work environment supports it.

The shared development of collaborative approaches within the care system may encourage HCPs to consider practices that are predominantly used in their work context and help them to identify existing facilitators and barriers. Adopting new behaviours may be disruptive for some HCPs because the transformative process may create insecurities that hinder implementation. The HCPs may experience insecurities because they are unfamiliar with or unsupported in the delivery of the new care approach.

### **8.3 Components of integration**

This section presents the components of integration (initially identified in the model outlined in Chapter 2, see Figure 2-2) and how they were revised to provide more detail in the way integration is expressed in the context of self-management education. The synthesis identified areas of confirmation as well as new insights and perspectives pertaining to relationships and interactions in self-management education. The revised components are described below.

#### **8.3.1 Person-centred care**

The component of person-centred care relates to the extent to which HCPs support people with T2DM by recognising their personal agency. This component, originally labelled as “interpersonal relationship”, considers the interactions between HCPs and patients that centre around the patient’s individual needs. These interactions are shaped by their outlooks regarding self-management education and are influenced by the care delivery system within which they interrelate. Active patient participation is important for supporting patients’ self-management behaviours. A key facilitating factor of this is HCPs’ skills in building an interpersonal relationship that fosters patient engagement and self-identification in their care, thus an integrated aspect of person-centred care.

As is evident in the data of Case A, strengthening their personal agency encouraged the patients to perceive themselves as able to negotiate their care by bringing their personality into the care conversation with HCPs. Supportive care should be based on a person-centred approach, and patients should feel represented and encouraged to take initiative and continue their learning for themselves.

### **8.3.2 Programme ethos**

The component of programme ethos is expressed in the underpinning theoretical framework, which provided the ethos for programme delivery. The labelling of this component remained unchanged because it considers the theoretical framework of programme delivery. The synthesis indicated that the programme ethos influenced the HCPs outlook of person-centred self-management support and in return shaped the way they conducted the programme.

The underlying programme ethos aimed to foster patients' confidence in actively participating in their treatment and interactions with HCPs, but it also nurtured the HCPs' confidence in co-creating interactions pertaining to care with patients. Furthermore, the data show how the ethos sought to harmonise the patients' experiences in self-management education with the care they might receive from an HCP who has been exposed to skills training in person-centred therapeutic education.

From the data, it is obvious that training HCPs in understanding the underpinning theoretical programme framework encouraged them to strive for a more congruent delivery when implementing person-centred self-management education.

### **8.3.3 Inter-professional work**

The component of inter-professional work relates to the extent to which professionals from different disciplines work with each other (originally labelled “shared learning”). The data suggest that this is mediated by HCPs’ willingness to share different understandings and by their openness (bi-directionality) to different ways of working with other HCPs and patients. In some cases, HCPs felt that they would be unsupported by their co-workers, particularly when a senior person may not have been receptive to changing an approach to patient care. As observed in the skills training programme, HCPs who felt that the approach they were learning would not be readily accepted by colleagues were less confident that they would be able to enact the programme’s model of care.

In that sense, inter-professional work could be enhanced by having all team members, including inputs from patients’ experiences, participate in a training programme to encourage shared learning, which is part of how collaboration may develop. In addition, the development of shared protocols and guidelines that incorporate the programme ethos may also help embed the care approach into care delivery.

### **8.3.4 Communal resources**

The component of communal resources (originally labelled as “adapting to context”) refers to adapting care to individual and community contexts. Communal resources are those that give access to self-management education and support, together with the local structures in which the different care processes are delivered.

The communal resources provided in the programmes of this study varied in relation to the individual (cultural, linguistic, psycho-social) and local needs of each specific context. For example, in order to give patients equal access to self-management education, members of the same healthcare team delivered the care in different

communal settings. They were observed as adapting their communication style and the words they used to the context of the group. In that sense, the delivery of self-management education connected to the patients' needs which were addressed by HCPs who used established local resources to ease the access to this kind of care in the community.

Self-management education was also provided by combining different learning resources outside of direct interactions and access in community settings. For example, patients mentioned using internet resources for information gathering or additional training, and some participated in online mobile learning programmes that integrated a virtual coach. Despite these easily available learning resources, some patients preferred direct contact with people for learning and social support. As the data in this study indicated, the experience with self-management education was shaped by the delivery form of self-management education accessible through communal resources, whereas online learning was perceived as an additional option for information transfer. Patients' direct exchanges with HCPs and peers shaped their experiences and for that reason they may have felt supported in their individual contexts. Favourable conditions may create an environment of social encouragement and therefore, help patients to develop self-management behaviour. However, these behaviours may cease if not supported in an individual context. Furthermore, communal resources may promote or limit the availability of the support provided, particularly with regard to primary care provision.

### **8.3.5 Programme regulations**

The component of programme regulations evolved from its original form of "care system organisation"; it describes the programme principles and guidelines that frame the implementation of self-management education and support in a given context. Although programme regulations are part of a care system organisation, it is

necessary to specify these regulations as an essential step to integrate self-management education into the system. This component is related to the guidelines, processes and structures that delineated the programmes and regulated aspects of their care delivery.

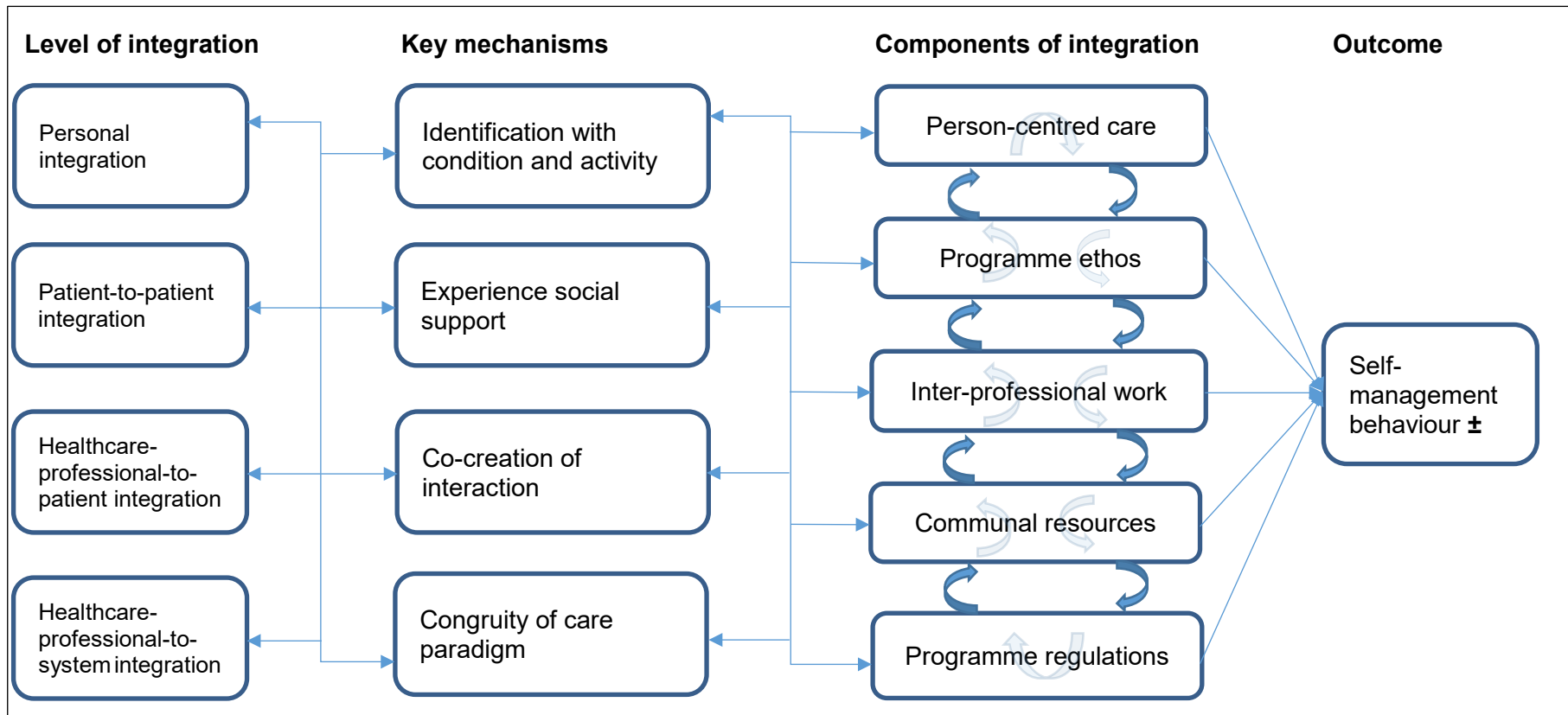
To address the multi-contextual nature of the programmes across areas and teams, clinical practice guidelines and recommendations were used to provide normative regulations to support programme delivery and identify benchmarks by which the programmes could be assessed. The use of common training programmes also served to regulate programme implementation.

#### **8.4 Interacting mechanisms and components of integration**

Having described the different mechanisms and components that seemed to be operationalised within the framework of integration observed, it was possible to build a model to conceptualise the mechanisms and components of integration interacting at multiple levels of personal, patient-to-patient, HCP-to-patient and HCP-to-system integration. The model explains how the mechanisms and components may interact at these levels to shape the different points of integration in relation to self-management education and support in routine care (see Figure 8-1).

The first column in the figure below identifies the different levels of integration observed in the programme. The second and third columns respectively delineate the key mechanisms and components expressed, and their potential impact on self-management behaviours is outlined in the fourth column.

This model explicates how integration was manifest in the programmes. It also provides a transferable interpretation of how integration might be conceptualised when considering models of self-management education and support for people with T2DM and with other chronic conditions.



**Figure 8-1 Key mechanisms and components of integration in the context of self-management education at multiple levels**



## **8.5 The logic model**

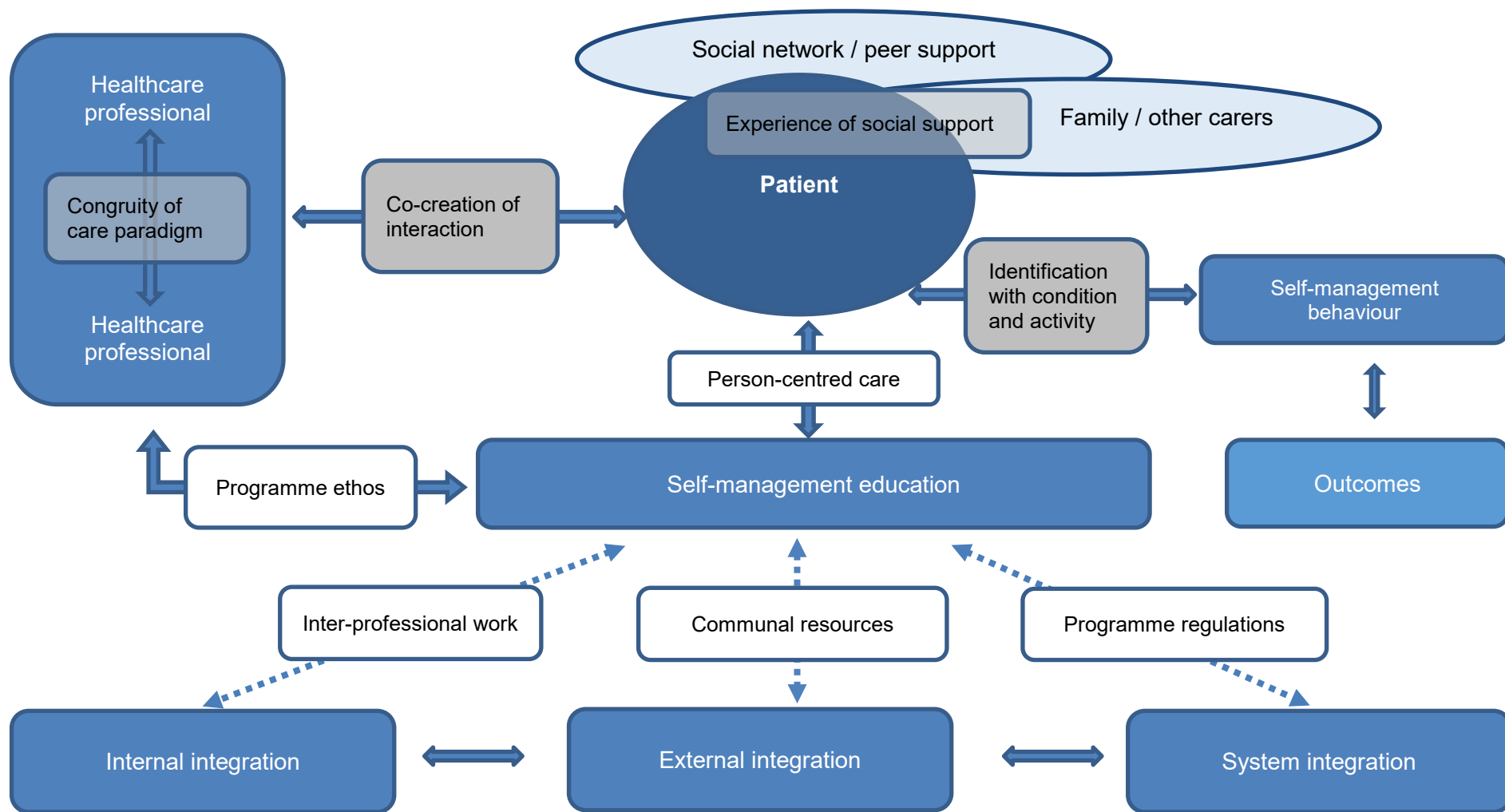
To conclude this synthesis, a logic model was constructed that reinterprets the conceptual model presented in Chapter 1. The revised model overlays the study findings based on the literature review in Chapter 2 and on the empirical study in order to convey how integration may be translated into programme delivery. This model then is adopted as the model of person-centred integrated self-management education. The logic model graphically describes the identified mechanisms and components of integration interacting in self-management education. The mechanisms underline the interactions that influence the adoption of self-management behaviour.

The model integrates the identified mechanisms from the collective cases with the components of self-management education. At the top centre of the model is the patient interacting within his or her own context within which he or she may experience social support. Describing the model counter-clockwise, the systems of patients and HCPs relate to each other through a process of co-creating interactions. The HCPs themselves build up a system that depends on how they perceive and congruently deliver the care paradigm. The component of a programme ethos explains the care paradigm used in self-management education.

The component of inter-professional work influences care delivery, and the internal team integration may affect patients' self-management support experiences. The component of communal resources connects self-management education to the context of care delivery in routine care. External integration may influence the care continuity experienced by patients. The component of programme regulations standardises self-management education and connects the programme to the care system. These components collectively provide a framework for the delivery of self-management education by multiple HCPs. If these factors are fully observed, it should

enable the delivery of a person-centred integrated model of self-management education and support.

Person-centred care may then in turn influence how patients identify with their condition and activity. This identification may affect their self-management behaviours and thereby impact treatment outcomes – and, ultimately, the patients' risk of developing diabetes complications. The element of training HCPs is active across the components and mechanisms and influences their interactions. The logic model of person-centred integrated self-management education is presented in Figure 8-2.



Colour scheme: conceptual framework blue; components of integration white; mechanisms of integration grey

**Figure 8-2 Model of person-centred integrated self-management education**

## **8.6 Summary**

This cross-case synthesis reveals new theoretical insights into how integration was expressed across the different factors of self-management education. This study findings identified four mechanisms and five components of integration that seem to influence how integration is mediated at patient, HCP and system levels. The synthesis also identifies a pathway to indicate the potential impact of these different components and mechanisms of integration as they pertain to self-management behaviours. Integration at the patient level refers to actions that individuals take in their daily lives to address their chronic condition and how they learn to live with it. Integration at the HCP level refers to person-centred care delivery to support patients' self-management behaviours and how HCPs collaborate between themselves to maintain support. Integration at the system level refers to the normative regulations to standardise self-management education delivery and how the care system organises the context to deliver such support. Moreover, because integration is complex, modelling its interactions and relationships contributes to a fuller understanding of the concept integration in the context of self-management education.

The synthesis also emphasises the value of developing programmes of self-management education and support that not only address the needs of patients but also provide HCPs with the skills required to continue this support in routine care. It also emphasises how the context of care, defined as the prevailing care paradigm within the care system, can improve the integration of patient self-management education into routine care.

These findings are discussed in the following chapter.

## **Chapter 9 Discussion**

In this chapter, the findings of the study are discussed in the context of prior knowledge and theory. The resulting insights are outlined and considered in light of how they may relate to practice of self-management education and future research. The study was designed to explore integration in the context of self-management education for people with T2DM in routine care.

The chapter is organised into sections that address the following areas: discuss the study findings in relation to previous research and theory to derive new insights; consider the study's strengths and limitations; and consider the implications of the findings for clinical practice, education and further research. The chapter finishes with a summative conclusion of the research and with an outline of how findings will be disseminated.

### **9.1 Integration of self-management education and support**

This study found that integration is an interdependent, multi-faceted process that manifests at multiple levels in the relationships between patients, HCPs and care systems. These relationships emerge from the extent to which supportive, collaborative and connected interactions are operationalised in self-management education. Moreover, the study findings suggest that the integration of self-management education into routine care also depends on HCPs adopting a new approach towards person-centred care delivery as well as on the care system providing comprehensive support for self-management. Both of those approaches would support patients in integrating self-management behaviour into their lives.

The findings are discussed below in relation to each of these levels. Moreover, significant interaction between these levels is evident, which is also considered.

### **9.1.1 The patient level**

At the patient level, the findings suggest that integration involves the interaction of internal and external processes. The internal processes relate to how patients identify with their diabetes and adjust their lifestyle and self-management behaviours to balance their glucose fluctuations. External processes relate to how self-management education connects with patients' life contexts and ongoing healthcare interactions.

The programme withdrawal in this context was very low; a few participants missed some sessions, but all finished the programmes. This finding is encouraging given that there is generally a high attrition rate in intensive self-management support and education programmes (Newman *et al.* 2004, Gucciardi 2008). This observed retention may suggest that the participants were generally satisfied or felt that their needs were being addressed by the programme, as is indicated in their narratives. Furthermore, giving participants' options may have reduced individual barriers related to constraints and increased the level of commitment. The findings also suggest the importance of social resources for sustainable outcomes of self-management education. Several participants have said that a supportive environment helped them overcome barriers and integrate their new skills and behaviours into their life contexts; these responses include those with low socio-economic status. Nonetheless, people from a more deprived social milieu may lack resources or have life burdens that impede their self-management (Di Cesare *et al.* 2013). Therefore, addressing individuals within their social-cultural-economic contexts is critical if the effect of self-management education should be maintained over time.

The patients' environments may be important in considering how self-management support programmes are designed and delivered. While the focus of the programme should be on supporting patients' individual integration processes, the delivery of ongoing

care must nurture positive self-identification with diabetes and its treatments. There also seems to be a need to equip patients with the skills they need to negotiate and integrate their disease needs into their daily life routines. The flexible, individualised approach to self-management support in this study may have encouraged this self-identification in some participants. Furthermore, focusing on the individual contexts of different patients may support them in recognising their own relationships with their diabetes and the requirements for a positive and healthy integration while considering their own needs.

These findings add to previous research that has emphasised how individual integration at the patient level is important in activating the processes necessary for a positive adjustment to chronic disease (Fleury 1991, Hernandez 1995, Hernandez 1996, Medich *et al.* 1997, Whitemore 2005, Whitemore & Dixon 2008, Hörnsten *et al.* 2011). Previous research has linked integration to individual normalising processes with associated cognitive strategies in how people perceive and normalise their disease experiences (Whitemore & Dixon 2008, Hörnsten *et al.* 2011). This is a non-linear process and can be unpredictable and uncertain. Such non-linearity was confirmed both in this study findings and in previous research that has described the integration process to disease experiences as akin to phases of grief (shock, denial, anger, bargaining, depression, acceptance and reorganisation) as patients' diseases disrupt their previous life assumptions (Roman 2006, Bussolari & Goodell 2009, Kahn *et al.* 2013, Stroebe *et al.* 2017). Hence, in structuring chronic disease education programmes so as to consider peoples' life context, engagement may be enhanced by recognising elements of this process as phases on a journey that influence patients' coping strategies and behaviours. Furthermore, although attending to this process of how individuals integrate their identity and diabetes was not an explicit intention of the programmes, the patients' accounts in this study suggest that this self-identification was important to their experience. Most

participants expressed that the self-management education they experienced helped them to integrate the behavioural practices needed to manage their condition within their daily routines more than they had been able to do so prior to attending the programme. Hence, it may be that programmes having an explicit focus on supporting people in self-identifying more positively with their diabetes and in acknowledging its emotional impact could enhance the effect of those programmes on the adoption of positive self-management behaviours. It is important to note that what has been described as individual integration in the findings makes a distinct but related form of the adaptive processes of living with T2DM (Whittemore & Roy 2002): It is distinct because it is specific to how the patients who are exposed to self-management education begin to integrate self-management behaviours into their routines, and it is related because, in doing so, they may be developing a more positive orientation towards their disease.

The findings also suggest that patients who are able to share their experiences with their peers may positively integrate self-management behaviours into their routines through group interactions. This may be because such interactions provide them with the opportunity to address some of the frustrations they have felt in living with chronic disease. Peer exchange may also help them normalise their perceptions – a process that may also partially reduce the psychological distress they experience on that journey. However, in contrast to the findings of this study, previous research shows that some participants also feel distressed and anguished through group interactions, especially when they perceive themselves to be doing less well than others (Rogers *et al.* 2009b); this indicates that a negative social comparison could possibly worsen some participants' engagement and self-management behaviour. Therefore, it is essential to create favourable conditions for peer support that reduce the emotional burdens patients may perceive in relation to their diabetes – as was captured in some of the patients' accounts after programme



participation. Again, this finding reflects other studies which have shown an association between emotional distress and diabetes self-management (Mosnier-Pudar *et al.* 2009, Huxley *et al.* 2015, Tang *et al.* 2015, Bennetter *et al.* 2016, Van Vugt *et al.* 2016). Hence, peer support as a self-management education strategy may address individual emotional burdens and help patients consider their own concerns if it is delivered in a supportive environment. In addition, the development of personal integration, as observed in this study, may also enhance self-management practices, thereby improving care outcomes. While more work is needed to determine whether this pathway of personal integration results in better diabetes outcomes, the structure of education programmes may be improved by linking how patients feel about their diabetes with their self-management practices. Therefore, an explicit focus on helping people self-identify more positively with their diabetes and on acknowledging the emotional impact of the disease could enhance the impact of self-management programmes on the adoption of positive self-management behaviours.

In terms of the mechanisms within the programme that seemed to activate personal integration, perhaps the most significant ones were identification with condition and activity and experience social support. The HCPs encouraged patients to voice their emotions and share their experiences by using metaphors to relate some of the inner thoughts and emotions that can occur in the experience of chronic disease. This makes sense because it has been suggested that metaphorical language can help people to interpret their symptoms and emotions (Czechmeister 1994, Lakoff & Johnson 2008, McFarland *et al.* 2009, Solberg *et al.* 2012). The study findings also suggest that sharing experiences and feelings in an environment that is supported by peers may have created the space for social bonding. As a result, it became possible to exchange experiences and inner thoughts in a commonly understood language and with similar interpretations.

Hence, integrating social support into programme delivery has been shown to help participants to identify with disease, which adds to findings of previous research (Deakin *et al.* 2006, Mandalia *et al.* 2014, Odgers-Jewell *et al.* 2017).

However, it has long been recognised that communication and specifically the use of metaphors may also create misunderstandings and contribute to negative stereotyping and devaluation of individuals, especially when indifferently used in discourse that is purely biomedical with little interaction and reflection to verify the individual meaning given to the metaphor (Sontag 1979, Lieban 1992). Therefore, care needs to be taken in how these metaphors are constructed and presented to people to ensure that labelling and devaluing personal experience does not happen in self-management education. In the context of this study, this danger was addressed by a separate programme (Case C), enhancing HCPs skills in delivering person-centred therapeutic education by encouraging them to consider their own positioning and use of language. As Bandura and Locke (2003) emphasised, using positive language may better encourage people than using expressions that can be related to poorer outcomes.

The findings also showed that some patients found the programme less beneficial, either because they felt that they had already established an easy rapport with their diabetes and did not receive new inputs or because they simply preferred to be given instructions and would have preferred to receive more advice from the HCPs. Such variety presents a challenge for self-management education because it indicates that patient needs are heterogeneous. Therefore, with respect to integration, patients may need flexibility and choice regarding their self-management support, which may be at odds with the prevailing structured approach to self-management education, as reflected in the study of Forbes *et al.* (2011).

It was also clear from the patients' accounts that the process of personal integration was mediated by external processes that interacted in the contexts of their lives and ongoing care experiences. These experiences may have an impact on self-management behaviour, independent of a given programme. When not addressed, they may impede the process of self-integration. These findings relate to the study of Snow *et al.* (2013), which found that self-management education may increase people's confidence and skills for handling their disease in daily life; however, a context in which patients' expertise remains unrecognised may hinder their active participation in interactions with HCPs because acknowledging that expertise may challenge the habitual positions of some HCPs as the authority in medical encounters. As a result, transferring knowledge and applying self-management behaviour in everyday life may weaken if not implemented in routine care and individual social experience. Moreover, as this study findings showed not all HCPs use the person-centred approach in their practice hindering a congruent care experience of patients. This underlines previous research showing that HCPs have different understandings in transferring responsibility of care: Some may interpret patients' self-management support as mainly carrying out tasks to control the condition while others enable patients to develop their own ability to actively influence medical encounters (Snow *et al.* 2013, Bostrom *et al.* 2014a, Morgan *et al.* 2017).

Also, other studies have explicated that in order to maintain self-management behaviour, patients may benefit from ongoing support by trained HCPs who comprehend the same care practices advocated in a programme (Rankin *et al.* 2012, Winkley *et al.* 2015). This may be because trained HCPs may reflect on the issues (which untrained HCPs may lack the skills to do), and such reflections may enable them to advance support and consider health-related stigmata that may be present. Health-related stigmata that may be expressed in language are widespread and associated with perceived higher levels of

distress and less social support – both of which may also result in unequal treatment and eventual exclusion (Nicolucci *et al.* 2013, Benedetti 2014, Gredig & Bartelsen-Raemy 2017). This issue was anticipated in the wider quality improvement strategy of the PcD, which integrated awareness training for HCPs. In this study, some of these aspects were identified, and the extent to which person-centred self-management support may have been realised was dependent on the context of care delivery, which is discussed below.

### **9.1.2 The healthcare professional level**

The findings of this study emphasise that, at the HCP level, integration centres on how HCPs interact with patients to provide ongoing support and relational care. In this study, their interactions were emphasised in how they responded to patients who were exposed to a self-management education programme that encouraged the patients' personal autonomy, motivation and shared goal-setting for self-management. The HCPs were specifically trained to deliver such programmes. The findings show that this approach requires HCPs to adjust their way of working to adopt a more person-centred model of care. Such an approach involves a different mind-set, as self-management support is not automatically integrated into professional practice and often requires additional training (Davies *et al.* 2018). Moreover, previous studies have shown that some HCPs may not be aware that their own perceptions of lifestyle-related conditions such as diabetes and obesity may impact their interactions and decision-making processes, as negative attitudes towards people with obesity are widespread even in healthcare settings (Mold & Forbes 2013, Jung *et al.* 2015). Also, some HCPs may lack knowledge enough to care for people with lifestyle-related conditions and may inadvertently disempower people, as less-experienced HCPs often perceive themselves to be able to deliver self-management support (Jallinoja *et al.* 2007, Entwistle *et al.* 2018, Torre *et al.* 2018).

A person-centred approach resonates with emerging evidence which shows that shared decisions to co-create care objectives are better accepted by patients and lead to better self-management engagement and clinical outcomes (Legare *et al.* 2010, Coulter *et al.* 2013, Tinelli *et al.* 2017). However, it is recognised that person-centred care requires HCPs to learn additional communication skills and behavioural techniques in addition to identify how their own values and understandings influence self-management support within their work context (Elwyn *et al.* 2017, Davies *et al.* 2018). This study points to the potential for variability in the implementation of person-centred self-management support, as some HCPs are enthusiastic about adopting a more person-centred approach, while others are resistant to this approach. The latter findings have also been reported in other studies, according to which some HCPs regard this way of working to be burdensome and impractical (Charles *et al.* 1997, Gravel *et al.* 2006).

As implied by Gravel *et al.* (2006), time constraints and disagreement on the applicability of patient involvement are commonly identified as barriers to implementing shared-decision-making in clinical practice. The lack of agreement may relate both to acute clinical situations that make patient involvement impractical and to HCPs' perceptions that patients prefer not to be involved. Furthermore, a knowledge-based asymmetry between HCPs and patients may produce imbalance in the relationship between the HCP and the patients, thereby inhibiting shared decision-making (Goodyear-Smith & Buetow 2001, Lieber *et al.* 2011). This study shows that the potential power imbalance in healthcare communications may be addressed through a complementary training approach for HCPs and patients, which may result in more equal interactions. Such an integrated approach encourages HCPs to consider their own morality in self-management support so that they understand what it is to enable patients: Recognising patients' individual abilities to participate in their own care helps both HCPs and patients to mindfully promote shared

responsibilities in their interactions without failing to reflect on social, cultural and economic constraints that may affect patients' health outcomes (Greenhalgh 2009, Pols 2013, Devisch & Vanheule 2015, Eliassen 2016).

Moreover, the HCP's training also addresses preconceived notions that may cause misinterpretation of patients' preferences and capabilities, thereby hindering person-centred care delivery. This finding complements the study of Gravel *et al.* (2006) that shows that many HCPs underestimate patients' capabilities to participate in shared decision-making. Hence, awareness-raising trainings help HCPs recognise their own barriers and further emphasises the importance of additional training in communication and inter-professional collaboration. Enhancing HCPs' skills and altering their position in self-management support helps connect patients' beliefs and values with clinical expertise in a chronic care context, which complements the understanding of previous research (Assal 1999, Anderson & Funnell 2005, Bostrom *et al.* 2014b, Friesen-Storms *et al.* 2015).

In contrast to most HCP participants in this study, HCPs in general may be unaware of the additional skills necessary for person-centred care delivery. As previous research has underlined, some HCPs respond in a normative way to individual needs, using an informative, structured approach to control patients' behaviour, which may also involve labelling the patients according to an externally set agenda (Snow *et al.* 2013, Bostrom *et al.* 2014a). In addition, as Kennedy *et al.* (2014a) found, some HCPs may adhere to organisational priorities and not initiate self-management support in routine care. Previous studies have also identified the need for additional professional training to improve HCPs' ability to meet the complex care needs of people with chronic disease (Assal 1999, Anderson & Funnell 2005, Holt *et al.* 2013, Lucey 2013). This need for further training is consistent with the emphasis on communication skills and collaborative care observed in this study.

In order to improve care delivery for chronic disease, professional training is needed that addresses HCPs' skills in person-centred communication strategies and inter-professional team-based collaboration. With respect to integration, such training may introduce a common training of multiple HCPs to prepare them for better interdisciplinary collaboration, which may be challenged by the often fragmented delivery of healthcare. This approach may involve rethinking relationships and dynamic interactions – not only between HCPs and patients but also among HCPs themselves.

In the context of this study, some HCPs were trained in therapeutic education, which refers to an advanced inter-professional form of training for person-centred chronic care support (Assal & Golay 2001, Golay *et al.* 2008, Golay *et al.* 2010, Sofra *et al.* 2014). The data of the inter-professional training component for HCPs in this study shows that the reflective process stimulated most participants to consider their professional practice and reflect on their positioning and perceptions of self-management education. Some specified that working in strict medical and management-oriented hierarchies discouraged them from using a person-centred approach. This is congruent with Mantzoukas and Jasper (2004), who suggested that authoritarian organisational structures may constrain reflective practice because it may challenge established roles and positions.

In addition, Rolfe and Gardner (2006) have argued that the problem may reflect a more profound tendency of HCPs to direct patients instead of responding to their needs. Such tendency may manifest in indifferently engaging in reflection while continuing to exert control over the discourse. Therefore, communication competencies of HCPs should be enhanced in routine care that features self-management as a significant element of care. Reflective practices could guide such improvement to ensure that HCPs may self-reflect on how they might enhance their interactions.

Some of HCP participants in this study recognised such shortcomings, as they identified their own need for additional training and practice to develop their skills. They also empathised the potential benefits of increased dialogue with their immediate team colleagues with respect to the methods and approaches they use to activate and encourage self-management. Challenging preconceived notions about what constitutes best practices at work may confront HCPs with practices that may not align with the person-centred care paradigm.

Moreover, certain reflections may provoke resistance to change amongst HCPs, who may realise that they are more comfortable in the authoritarian position of an expert. Consequently, they may feel insecure about adapting to person-centred approaches, which is congruent with previous research (Piderit 2000, Plsek & Wilson 2001, Carlström & Ekman 2012, Schilling *et al.* 2012). As these earlier studies suggest, resistance is often based on an emotional reaction to a perceived loss of control or status, for example, or a general anxiety about or misunderstanding of a new concept. These triggers may imply that resistance should be overcome instead of supporting the integration of patterns that attract change.

Hence, to fully integrate a new philosophy of self-management support as part of an education programme also necessitates organisational change if that approach is going to be reflected in the patients' experiences beyond attending one course. Indeed, not doing so may arguably cause harm by creating false expectations amongst patients about the experience of the education programme and their daily care, which could lead them to become frustrated and negate the benefits of the course. This shortcoming of self-management education programmes that espouse a person-centred approach without integrating the same approach into routine care has been highlighted in other studies (Balcou-Debussche & Debussche 2009, Forbes *et al.* 2011). Therefore, an important



mechanism associated with integration at HCP level is the congruence to which the HCPs adopt the care paradigm that underlies the programme ethos of self-management support. In doing so, they may deliver a more continuous care experience of patient support and could contribute to the development of a network of care, as implied in some narratives in the study data. Similar to this study finding, Fix *et al.* (2018) have suggested that a comprehensive approach to person-centred care is only possible if a whole-system approach is adopted to ensure that all elements of the care experience are connected to this ethos. Furthermore, surveys of patient preferences for self-management support have emphasised care continuity and communication as some of the most important elements (Forbes *et al.* 2010). Therefore, as in this study observed, adopting a comprehensive approach to person-centred care that is implemented in a whole-system approach may necessitate additional professional training in person-centred care, communication and the construction of supportive care relationships. Such training could better equip HCPs to establish care networks, which in turn would allow patient participants to extend the person-centred care experience in their context.

### **9.1.3 The system level**

At the system level, the findings suggest that integration is shaped by the organisational structures that prevail within the wider healthcare context and in the structures and processes used to connect the self-management education principles to that context. These structures and processes are characterised as operating at the levels of internal, external and system integration. Internal integration at the system level relates to the team structures that may further inter-professional collaboration. External integration at the system level relates to the delivery structures and resources that may foster coordination and enhance continuous care support while flexibly adapting to local conditions. System

integration relates to the normative regulations that assess the delivery according to defined guidelines and recommendations. In this study context, these system components were considered from the outset of the PcD to create the conditions for integration to evolve (Hagon-Traub *et al.* 2010).

In relation to internal integration at system level, the interdisciplinary diabetes team members of this study perceived collaborative care as important, although collaboration had not yet been fully implemented in all contexts. This is in accordance with a recent study by Schweizer *et al.* (2017), who, in the context of PcD, indicated a difference in perceived collaboration between HCPs in specialist care and those working in primary care. They found that although the degree of collaboration was generally perceived to be higher in primary care, concerns were also raised about losing patients to specialists. While this might suggest a disagreement over the perceived power shift of responsibilities, it might also reveal a lack of skills in how to best implement collaborative care between different settings as well as a possible role conflict (Schweizer *et al.* 2017).

Moreover, in addition to reflection on their work practice, the interdisciplinary awareness training also encouraged HCPs to consider the likelihood of collaborations, which is in line with previous research suggesting that inter-professional education may lead to better collaboration, which in turn may improve patient outcomes and care processes (Reeves *et al.* 2009, Reeves *et al.* 2013). Furthermore, as the study of Lemieux-Charles and McGuire (2006) implied, outcomes may be largely influenced by positive communication patterns observed in team collaboration and by coordination within the context where the healthcare team interacts.

In this study context, the participants of the awareness-raising programme (Case C) mainly used respectful, encouraging language in their group interactions, which may

indicate an effective collaborative team process, although communication patterns were not observed in their specific, real-life contexts after programme participation. Therefore, it remains unclear if and how they were able to implement and build on these learning experiences. Previous research suggests that collaboration across sectorial and organisational boundaries may be challenging because various dynamics interact in the different community resources involved in the continuous delivery of self-management support (Goderis *et al.* 2010, McDonald *et al.* 2012, Russell *et al.* 2013, Jaffe *et al.* 2015, Schoenbaum & Okun 2015). As indicated by McDonald *et al.* (2012), ongoing care is best delivered by multiple HCPs working together, although power dynamics related to protecting self-interests or striving for influence may impede shared decision-making, which may also be related to a lack of trust. Again, collaboration may relate to acceptance of other HCPs' roles and positions, thus transcending an understanding of professional identities and adding another layer of complexity to relationship-building across professional groups and services. That complexity may create further uncertainties which may directly influence patient experiences (McDonald *et al.* 2012).

Inter-professional education and collaborative practice is broadly recommended (WHO 2010), but the implementation remains challenging because context-specific discrepancies may mean expecting the HCPs to deliver person-centred care with restricted resources – which naturally would affect performance (Byers 2017). However, as Byers (2017) found, investing in HCPs to lead change may improve healthcare delivery. Organisational support may encourage the implementation of an integrated approach to person-centred care when considering the broad varieties of local care developments that are led by HCPs with clearly defined roles (Van der Vlegel-Brouwer 2013, Ku & Kegels 2014, Eyre *et al.* 2015, Byers 2017, Schussele Filliettaz *et al.* 2018). An identified common vision and commitment to favouring care integration at the system

level, as reflected in user and stakeholder involvement, is consistent with previous research (Kodner & Spreeuwenberg 2002, Shaw *et al.* 2011), although improving collaboration across inter-professional and inter-organisational boundaries remains challenging (Karam *et al.* 2018).

In addition to inter-professional collaboration, implementing care in diverse contexts to a certain standard may be facilitated by having clear guidelines and recommendations. This is true even though such standards are not always followed, most often due to a lack of agreement or evidence, organisational constraints or unclear recommendations, as found by Lugtenberg *et al.* (2009). To address these issues, the quality improvement strategy of PcD developed guidelines and recommendations adapted to local context in collaboration with HCPs from a wide variety of disciplines and specialities (Programme cantonal Diabète 2017).

While standards and organisational support may ease implementation, the integration of person-centred self-management education and support still depends on human dynamics, which are manifest and active in an organisation. However, an organisational culture that supports flexibility, cohesion and trust may better integrate person-centred care. This connection relates to the study of Carlström and Ekman (2012), which also underlined the importance of a context for implementation. Furthermore, while this endeavour was not part of a nationwide whole-system revision, it did help ensure some connection between the different systems that interact in self-management education programmes; in particular, to integrate the patients' experiences of the education programme with the skills of HCPs to foster an ongoing self-management support following the programme participation. A lack of this continuity may also partly explain why

a number of structured education programmes for T2DM have yielded disappointing medium- to long-term outcomes (Khunti *et al.* 2012).

In view of the insufficient integration of self-management education in routine care, it may be important to develop and invest in the human relationships that create the conditions to build an organisational culture for person-centred ongoing support of patients. The findings also suggest that a whole-system approach should be mandated in the design and implementation of self-management education programmes to ensure connectivity between the education of patients and the wider context of their healthcare support in addition to access to ongoing self-management resources. This latter point is discussed further in the next section.

## **9.2 Integration of interactions at the different levels**

This study reveals that the integration of person-centred self-management education is related to patient participation and involvement, to the relationship between patients and HCPs and to the context of care delivery. These interactions require both patients and HCPs to adapt behaviours which support individual self-management.

It is important to note that what has been described as integrating self-management education into the delivery processes by developing a shared-care philosophy is distinct from but nonetheless related to the concept of care continuity, which contains relational, managerial and informational elements embedded in a whole-system approach to chronic care (Haggerty *et al.* 2003, Raaijmakers *et al.* 2013). Integrating a shared-care philosophy into self-management education expands on the concept of continuity with the HCPs' common understanding of person-centred care delivery. It thus contributes to more coherent care experiences of patients along their care path. Raising awareness of the skills needed by both HCPs and patients to encourage consistent self-management is

essential to the maintenance of care over time. However, these processes may be hampered through a fragmented care delivery and possible cross-purposes of people involved. For this reason, adding a flexible but consistent line of support responding to patient's changing needs in a complementary and timely manner contributes to a continuous care approach. Hence, integration relates to continuity in the sense that the strategies observed in the care system encourage self-management support in patients' routine care.

Integration also relates to communication and to transferring information between patients, HCPs and system levels. These processes can be eased by using information technology, for example, to transmit and document patients' past events and personal circumstances. Moreover, current developments are directed towards using e-health technologies and mobile health applications for self-management support. In addition, some data-sharing systems directly integrate patients' monitored data into their electronic health record and provide automated, patient-specific clinical decision support (Hess *et al.* 2007, Peeples *et al.* 2013, Cahn *et al.* 2015). Such interventions exhibit some beneficial effects, most of which are related to increased therapy adherence or to the acquisition of skills and techniques (Free *et al.* 2013, Torbjornsen *et al.* 2018). Patients are also increasingly expected to track their activities and manners via wearable devices to engage in self-care and provide relevant information regarding their behaviours in real-time so as to share this data with others and thereby actively contribute to their own healthcare (Ziebland & Wyke 2012, Lupton 2017). The integration of digital health technologies is of great potential benefit for patient care because they emphasise the prevention of an event through self-tracking, but this self-quantification has also raised ethical concerns related to patients' autonomy, external influences on decision-making, confidentiality and third-party monitoring of health treatment (Klugman *et al.* 2018, Moerenhout *et al.* 2018).

Therefore, it is essential to consider carefully how these technologies and the interpretation of patient data influence human decisions for not unreasonably controlling human behaviour and involuntarily hampering with patients' rights for autonomous decision-making processes. Such decisions require ethical reflections within clear regulations besides knowledge and skills in both patients and HCPs as they may have wide-reaching consequences for self-management support.

In addition, digital health technologies and mobile health applications may cover some aspects of self-management support, but they are rarely sufficient to fulfil patients' social support needs, as this study findings showed with patients participating in peer support groups after e-learning programmes. Some people prefer direct interactions between peers and HCPs for learning, which confirms that social contact helps in translating knowledge so that it can be useful in patients' daily lives as shown in previous research (Pols 2013, Hughes *et al.* 2017).

Therefore, understanding the concept of integration enlarges relational, managerial and informational aspects of continuity by combining essential components and mechanisms that facilitate a more coherent self-management support experience for patients in their routine care.

Embedding self-management support in routine care delivery requires a continuous engagement in events that involve patients and HCPs to integrate their experiences and share their understandings. In doing so, contexts may be created that enable patients to develop their self-management abilities, considering their values and preferences. Such emergent interactions between HCPs and patients may be operationalised by identifying with condition and activity besides experiencing social support that fosters the behaviours. Furthermore, HCPs skills to consistently deliver care to support self-management may

create conditions for co-creating supportive interactions that maintain self-management over time. Hence, understanding the activities that shape HCP and patient interactions contribute to how the patients are supported with their self-management behaviours. These implementation processes also require financial investments to maintain these programmes and regularly embed them in routine practice. Investing in the education of both HCPs and patients is valuable if self-management is to be normalised. By developing an in-depth understanding of the components and mechanisms needed to integrate self-management support into routine care so as to sustain self-management behaviour, this study complements previous research on the implementation processes required to normalise an intervention in routine care (Kennedy *et al.* 2014b, May *et al.* 2016).

The findings of this study also imply that patients' self-management behaviour needs to be addressed through parallel processes: Helping patients understand their tasks in self-management and integrate that understanding in their daily lives in parallel with ensuring that HCPs have the skills they need to create an environment that supports patients with this. At the core of this process is the need to support HCPs in learning how to interact with patients and listen to what they say. For some patients, it may still be common to agree with what HCPs prescribe, but it is important that patients learn to raise questions and voice their expectations so as to help HCPs tailor treatments according to their individual beliefs and values.

However, the data also reveal certain disparities in the way healthcare is organised. In some contexts, person-centred care delivery may be disconnected from the overall care system. This disconnection may be attributed in part to system-level priorities and the prevailing culture of care within them and in part to the inherently complex nature of diabetes and the heterogeneity of perspectives amongst the population with diabetes. Previous studies have emphasised that underlying factors, such as the education level



and socio-economic status of patients, have an impact on health outcomes and affect self-management intervention (Di Cesare *et al.* 2013, Devaux 2015, Mendenhall *et al.* 2017, Singer *et al.* 2017, Spini *et al.* 2017). Such studies have underlined the multiple social, psychological and biological factors that interact within a socio-economic and physical environment to shape patients' health behaviours, as these factors may lead to the health inequities that are evident in care outcomes (Devaux 2015, Murtin *et al.* 2017). Multiple studies have also illustrated the potential effect of these issues on participation in self-management programmes by revealing that individuals from more deprived backgrounds are less likely to attend (Winkley *et al.* 2016, Horigan *et al.* 2017).

The universal healthcare-coverage system in Switzerland requires patients to contribute a 10% cost participation to their healthcare. This obligation may cause certain patients to underuse care resources or renounce their healthcare (Wolff *et al.* 2011). Hence, it is possible that the most vulnerable patients at the highest risk of detrimental health consequences of diabetes may not participate in self-management education, which could further increase health inequities. To address health inequities in this context, the PcD quality improvement initiative has, beside other strategies, recommended the direct interaction of medical and social services in the community to more accurately identify health disparities and improve access to care for individuals in vulnerable situations (Hagon-Traub *et al.* 2017).

Integrating self-management education within a whole-system approach is also critical to enhancing care for people with chronic diseases (Wagner *et al.* 1996, Wagner *et al.* 1999, Bodenheimer *et al.* 2002a, Bodenheimer *et al.* 2002b, Bodenheimer *et al.* 2002c). To explicate how the components and mechanisms of integration observed within this study relate to the whole-system perspectives in self-management education, the findings were integrated across the different levels using the CAS model.

### 9.2.1 Complexity in self-management education

To relate the study's findings to the CAS model perspectives, self-management education is characterised by its non-linear interactions between the components of integration, the behavioural patterns that emerge from such interactions, the dynamic co-evolution of the related systems (often guided by simple rules), and self-organisation to adapt to the context. The findings complement recent studies that have underlined the importance of understanding relationships and interactions to improve healthcare delivery (Braithwaite *et al.* 2018, Greenhalgh & Papoutsis 2018, Grudniewicz *et al.* 2018, Khan *et al.* 2018, Reed *et al.* 2018). These studies have discussed the complexities of integrating change into healthcare delivery. They have also stressed the need to recognise the interconnectedness of system components while understanding the interactions and relationships of these systems and accepting that such behaviours may be unpredictable in certain contexts. In CAS, the transformational processes may be guided by simple rules, such as understanding the problem, practices and processes of care, identifying systemic issues, engaging people and sharing learning (Reed *et al.* 2018).

In this study context, the behaviour of systems is influenced by the mechanisms of integration. Independent of a programme, the way in which patients identify with their condition and activity shapes their participation. Therefore, a stronger emphasis on the opportunity to interact and share experiences within programmes could enhance their active contribution. Congruently extending the support experience into their routine care may further engagement, which could in turn promote self-management behaviour.

From the CAS perspectives of this study, self-management education would require programme design to operationalise its approach by incorporating the nested systems that represent the patients in their environments, the HCPs and their understanding of

care and self-management, and the care system, which includes training support for inter-professional working, community resources and programme regulations.

The study data suggest that interactions often depend on prior life experiences and current life priorities and perspectives. Therefore, the consideration of patients within their whole, individual context is crucial to support their self-management from a system perspective. This insight adds to the understanding of previous research on social determinants of health which may affect patients' health outcomes (Unwin *et al.* 2010, Clark & Utz 2014, Weaver *et al.* 2014). Hence, it is logical to integrate reflection on related but distinct systems of HCPs and system components into patients' systems, as they interact and construct a whole-system approach to self-management education.

The study's findings additionally imply that various tools may assist HCPs in assessing individual patients' needs and implementing the person-centred care approach. Nonetheless, it may be necessary to adapt these strategies to consider socio-cultural factors that can have an overriding impact on health behaviours (Hinder & Greenhalgh 2012, Debussche 2014, Masupe *et al.* 2018). While such factors were not obvious in this study, the data indicate that some patients preferred more direct interventions because they did not perceive the person-centred model of care as reflective of their needs. Rather, they found concrete instructions more appealing. In view of this, different approaches to self-management education may be needed to address the complexity that emerges from the diversity of participant expectations.

Active patient participation and interaction depend also on group compositions. They may challenge patients to mingle with the group and self-organise and prompt the HCPs to interrelate, as these interactions can distribute control over self-management education programmes. In the cases that this study has observed, most HCPs allowed dynamic relationships to guide group interactions. Such unstructured interactions require specific

skills of HCPs, such as a responsiveness to person-centred care delivery. Hence, additional training for HCPs may prepare them to manage unpredictable interactions that may emerge from the variation in patient perspectives and expectations that determine the group dynamics. Such unpredictability may also provoke tension, and some HCPs may feel uncomfortable and challenged by patients' contributions to their self-management education.

Hence, this study has usefully employed the CAS perspectives within a whole-system approach to produce a rich, nuanced picture for integrating self-management education into routine care. The importance of theoretical modelling and having an in-depth and contextual understanding of the target behaviour has been emphasised in guidelines for the development of complex programmes and interventions (Craig *et al.* 2008, Craig & Petticrew 2013, Yardley *et al.* 2015). This knowledge can inform the development of care delivery to maximise the potential benefits of self-management education programmes that can improve patient outcomes.

### **9.3 Strengths and limitations of the research**

The key strength of this study is its focus on an in-depth exploration of integration which is related to self-management education programmes in routine care. The study considered existing programmes to explore the concept of integration from multiple perspectives – at the patient, HCP and system levels – by providing a rich, detailed description of integration in the context of self-management education. This contributes to a comprehensive understanding which is needed to address the challenges in implementing self-management education in real-world settings so as to encourage sustainable self-management behaviour over time.

This study has a number of limitations. First, only participants (patients and HCPs) in the three cases were eligible to participate in this study, and they were recruited in the context of the quality improvement strategy. This may have attracted highly committed, self-selected volunteers, thus leading to selection bias with a subsequent impact on the data collected. Selecting only members from the cases may have precluded participants who may have been less proactive or people who are from certain social and economic groups. While this may limit the interpretations of these findings to the study context, the theoretical models used to explicate them facilitate perspectives that may be transferred to other settings. Furthermore, the socio-demographic characteristics of patient participants were observed to reflect the background population; hence, in this context, the sample is representative of that population. Second, the study perspective was limited by the use of single interviews at a point of time, thus precluding a longitudinal perspective regarding how participants' perspectives may have changed. However, the study combined different data collection methods and considered a contextual relationship of the data. In addition, the observations were conducted at different occasions during the programme, although how the participants operationalised their learning in their daily

routine or clinical practice was not observed. However, given the depth of inquiry, such observations were prohibitive. Despite these limitations, the study provides novel insights regarding the collective components and mechanisms impacting the integration of self-management education into routine care. It also provides a platform for future prospective studies in which the longer-term impacts could be considered in other health contexts.

#### **9.4 Implications for clinical practice and further research**

The observations and theoretical insights identified in this study provide some useful perspectives regarding how self-management education and support programmes might be enhanced and studied in the future. From a clinical perspective, the key recommendations from the study include the following:

- Develop personal integration by helping patients incorporate self-management behaviours into their life routines. This should be a core target for educational intervention and must be considered in the development of educational programmes. Strategies to enhance personal integration need to address how people identify with their diabetes and, in particular, should determine their emotional perspective on the disease. Strategies should also consider the wider life context because the social determinants of health seem to be important in regulating self-management behaviours.
- A parallel training programme for HCPs, in addition to self-management education for patients, should be considered to ensure that HCPs have the skills and understanding they need to respond to patients' needs and help them sustain the personal self-management plans they develop in the patient education sessions. This educational program should ensure that HCPs are familiar with the programme and are competent to work with patients in a way that reflects the

person-centred therapeutic education model. It is anticipated that the impact of the patient programme may thus be sustained. A central component of the HCP training should be to provide HCPs with enhanced communication and relation-building skills.

- When designing self-management programmes, it may be useful to undertake a whole-system analysis and introduce intervention to address any systemic issues or care practices that may inhibit the impact of the intervention. This will demand multiple levels of integration: of the way that the care system is designed, of the community and other social resources available to support patients, and of HCPs training with respect to the prevailing ethos or culture of care. This may indicate the need for a whole-system re-design to ensure that the working context of the HCPs and the care environment for patients include the ethos and values of the programme. Such an improvement strategy may also require maintenance support and process measures to ensure fidelity with the programme ethos and thereby ensure sustainable integration at the levels of patients, HCPs and care systems.

In terms of future research, this study has highlighted a number of areas for further inquiry as well as useful theoretical perspectives for supporting such inquiry. It is also important to recognise that the findings of this study are purely qualitative and that further research across different research paradigms (qualitative, quantitative and mixed methods) is needed (Creswell & Clark 2017). Future research might consider the following areas:

- Use the theoretical observations generated by this study to develop quantitative survey instruments which can measure the extent to which integration is implemented in different contexts and at different levels. Such instruments could then be validated to establish their capacity to discriminate different integrational

components and their association with patients' self-management behaviours and care outcomes.

- Health economic analyses might be used to model the impact of different thresholds of integration at different levels regarding the cost-effectiveness of the self-management programmes. Such studies could involve the analysis of existing programmes to assess the relationship between the level of observed integration at the patient, HCP and system levels so as to ascertain their impact on outcomes.
- Study interventions to help HCPs deliver self-management support in terms of skills, attitudes and behavioural competences to establish relationships with patients. Such interventions could consider the different elements of HCPs' training in therapeutic education, which in turn might enhance the impact of the patient self-management education programmes.
- Existing self-management support interventions need to be evaluated with patients to adapt the level of language used to their needs. Self-management education and support programmes can contain complex language and may be inappropriate for people with low educational backgrounds and from different social contexts.
- Future studies could widen perspectives with respect to how integration might manifest in the delivery of self-management education programmes to study the interactions with broadened multi-professional healthcare teams (e.g. pharmacists), and in relation to other constituents such as service managers and policy makers.
- Involve patients, HCPs and stakeholders who represent the care system within the research process so as to help refine and optimise self-management support programmes, thereby enhancing their acceptability, up-take, utility, deliverability, stability/fidelity and effectiveness in real clinical practice.



## **9.5 Conclusion**

The integration of self-management education into routine care is a multifaceted construct shaped by dynamic relationships emerging between interacting systems which are embedded in the context of self-management support delivery. The study conceptualises integration here in terms of components and mechanisms of integration that interact at and between the patient, HCP and system levels. The identified components and mechanisms propose a thorough understanding of interactions observed in these systems and explain their connectedness.

Personal integration occurs through identification with conditions and activities which are linked to and possibly enhanced by social-support experiences, for example, from next of kin or peers. Peer interactions help patients envision similarities and differences in disease perceptions and treatments, and this understanding supports them in living with conditions. Such interactions also relate to HCPs, who can learn from the patient experience whether they are prepared to equally consider the contributions of patients. This understanding furthers the successful implementation of self-management education in routine care by taking into account the expectations that people with T2DM have after programme participation.

Then again, patients' expectations link to HCPs' perceptions of facilitating individual patient support, which implies that HCPs should also reflect on the extent to which they and existing structures in the healthcare system may impede the implementation of a person-centred care approach. Such a demanding undertaking requires skilled HCPs for the delivery of self-management support. Moreover, the HCPs' training connects to the care system in relation to inter-professional working, community resources and regulations which are relevant to the delivery of self-management education.

Understanding of these interactions is needed to ensure optimal implementation of such interventions in routine care so that they become regularly embedded in practice processes.

These interactions are illustrated in the model of person-centred integrated self-management education, which is based on a rich picture of a complex phenomenon that draws together different kinds of data from multiple sources at different levels. The model considers the whole-system approach observed in chronic care while reflecting on the unpredictable and uncertain dynamics of CAS. The understanding from the study contributes to programme development and is helpful for using self-management education to ease the negative health outcomes of T2DM on individuals, their families and wider society. Therefore, this study is an important initial step in the processes of normalising the delivery of self-management education in routine care.

## 9.6 Dissemination of findings

Data from the study have been presented to patients, HCPs and stakeholders at local and regional meetings. In addition, data from the study have been presented at the following national and international conferences as oral and poster presentations:

### Poster presentation and conference papers:

- 2018 Huber C., Montreuil C., Forbes A. *Key components and mechanisms in the integration of self-management education in routine care of people with type 2 diabetes*. Paper presented at the 54<sup>th</sup> Annual Meeting of the European Association for the Study of Diabetes (EASD), Berlin, Germany, October 2018
  
- 2017 Huber C., Montreuil C., Forbes A. *Multilevel model of integrated self-management education in people with type 2 diabetes: a qualitative study*. Poster presentation at the Congress of the International Diabetes Federation (IDF), Abu Dhabi, United Arab Emirates, December 2017
  
- 2017 Huber C., Montreuil C., Forbes A. *Healthcare professionals' identity and therapeutic relationship in self-management support of people living with chronic conditions*. Poster presentation at the joint Conference of the European Academy of Nursing Science (EANS) and the Swedish Society of Nursing, Malmö, Sweden, July 2017
  
- 2016 Huber C., Sturt J., Chinn D., Montreuil C., Forbes. *A critical interpretive analysis of interacting factors in educational programmes for self-management in patients with type 2 diabetes*. Poster presentation at the European Academy of Nursing Science (EANS), Halle, Germany, July 2016

- 2016 Huber C., Sturt J., Chinn D., Montreuil C., Forbes. A. *Facteurs interagissant dans les programmes d'enseignement à l'autogestion auprès des patients diabétiques de type 2: une synthèse critique interprétative*. Poster presentation at the 6<sup>th</sup> European Congress of Therapeutic Patient Education (TPE), Geneva, Switzerland, May 2016
- 2015 Huber C., Chinn D., Sturt J., Forbes. A. *Integrated self-management education in type 2 diabetes: a critical interpretive synthesis*. Poster presentation at 20<sup>th</sup> Conference of Foundation of European Nurses in Diabetes (FEND), Stockholm, Sweden, September 2015
- 2015 Huber C., Chinn D., Sturt J., Forbes A. *Eine kritische Interpretation der integrierten Selbstmanagementschulung von Menschen mit Typ 2 Diabetes*. Poster presentation at the Annual Conference of the Swiss Nursing Association (SBK-ASI), Montreux, Switzerland, May 2015

#### **Oral presentations:**

- 2016 Huber C. *Integrated self-management education in type 2 diabetes: a critical interpretive synthesis*. Oral presentation at the 16<sup>th</sup> European Doctoral Conference in Nursing Science (EDCNS), Bern, Switzerland, September 2016
- 2016 Huber C. *Integration von Programmen zur Förderung des Selbstmanagements*. Oral presentation followed by a workshop discussion at the Annual Conference of the Swiss Organisation of Diabetes Specialist Nurses (SIDB-GICID), Bern, Switzerland, March 2016

**Planned future dissemination:**

2019 Oral presentation and workshop discussion (together with PcD) at the Annual Conference of the Swiss Organisation of Diabetes Specialist Nurses (SIDB-GICID), Bern, Switzerland, March 2019

**Papers in preparation:**

- Conceptualising integration in relation to self-management education for people with type 2 diabetes: a systematic review using principles from critical interpretive synthesis
- Healthcare professionals' identity and the building of therapeutic relationships: a qualitative study on interactions of self-management support in people living with chronic conditions
- Development of a multilevel model of integrated self-management education in people with type 2 diabetes: a qualitative study
- Understanding factors that influence the integration of self-management education into routine care of people with type 2 diabetes: a case study

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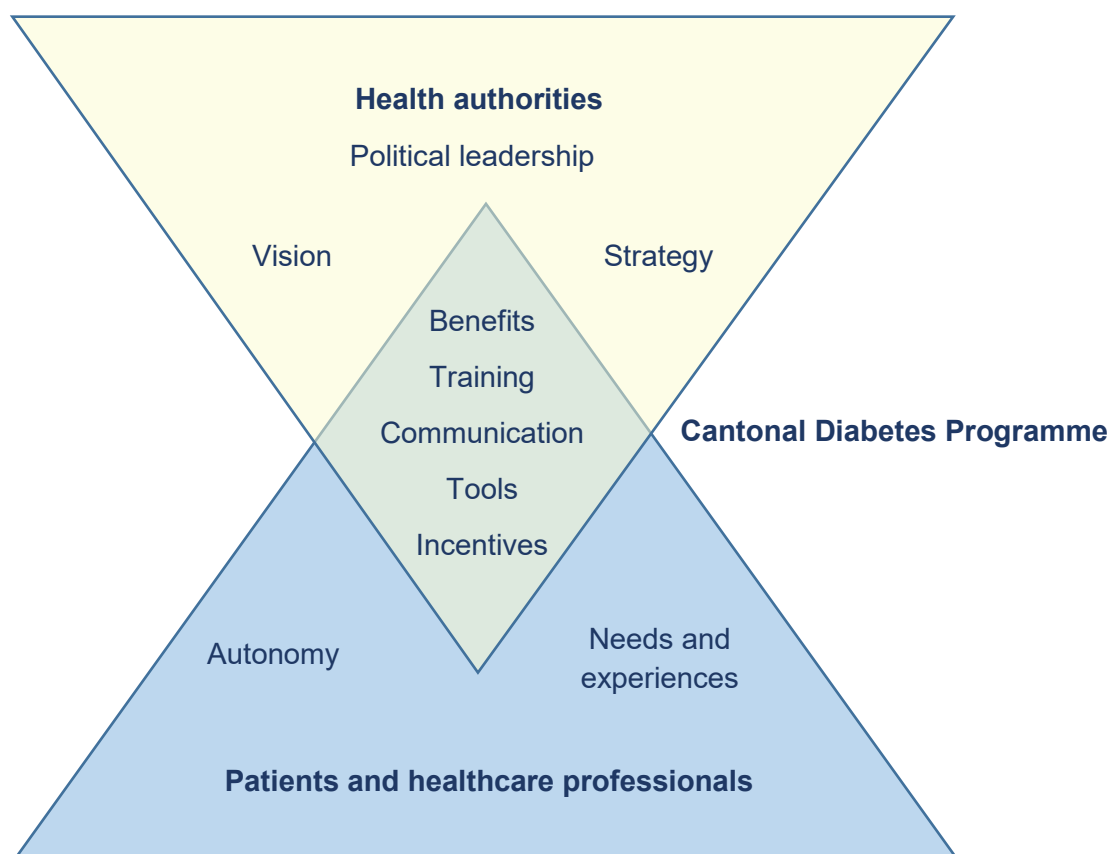
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## Appendix I Cantonal Diabetes Programme (combined approaches)

An overview of the bottom-up and top-down approaches used in the Cantonal Diabetes Programme is illustrated in Figure I-1.





**Figure I-1** Combined approaches of the Cantonal Diabetes Programme, adapted from Hagon-Traub and Chinet (2013)



## Appendix II Cantonal Diabetes Programme (project list)

(Translated with permission of the Cantonal Diabetes Programme)

 			[Colour scheme:]									
Cantonal diabetes programme 2013–2017 List of projects Version 11.02.2016			Projects resumed for piloting by SSP or RS		Ongoing projects		Completed projects to put forward		Projects to sustain		New projects 2016	
Line	Projects	Organisations in charge	2010	2011	2012	2013	2014	2015	2016	2017		
A SELF-MANAGEMENT AND SUPPORT	Empowerment état des lieux et propositions - mandat SSP PcD <i>Empowerment: assessment and suggestions – SSP PcD mandate</i>	PcD and partners										
	DIAfit	PcD - CHUV										
	EVIVO - Vivre avec une maladie chronique <i>Living with a chronic disease</i>	PcD - AVD - RS										
	Activité physique chez l'enfant <i>Physical activity for children</i>	PcD - PSHL-CHUV-AVD					2014					
	Programme patients experts AVD <i>AVD's expert patient programme</i>	PcD - AVD						2015				
	DIAfood	PcD - HES-SO						2015				
B MANAGEMENT	Pôles spécialisés - mandat SSP PcD <i>Specialised centres – SSP PcD mandate</i>	PcD - CHUV								2016		
	Diabète gestationnel PII [phase II] - intégration des soins <i>Gestational diabetes phase II – integration of care</i>	PcD - CHUV								2016		
	Rétinopathie diabétique <i>Diabetic retinopathy</i>	PcD - AOVD, HOJG-IUMSP								2016		
	Filière "néphropathie diabétique" <i>"Diabetic nephropathy" stream</i>	PcD - CHUV					2014					
	Dispositif diabète - Transition RSRL <i>Measures for diabetes – transitioning to the RSRL</i>	PcD - RSRL								2016		
	Dispositif diabète - Réseau de soins Nord Broye <i>Measures for diabetes – Nord Broye care network</i>	PcD - RSNB								2016		
	DiabOuest <i>Diabetes West</i>	PcD - RSLC						2015				
	DiabEst <i>Diabetes East</i>	PcD - RSHL						2015				
	Filière de diabétologie pédiatrique de l'Est vaudois <i>Eastern Vaud paediatric diabetology stream</i>	PcD - PSHL										
	Equipes interdisciplinaires - mandat SSP PcD <i>Interdisciplinary teams – SSP PcD mandate</i>	PcD and partners								2016		
	Renforcement des ressources infirmières spécialisées en diabétologie <i>Strengthening nursing resources specialised in diabetes care</i>	PcD - AVD										
	Podologie I - suivi systématique coordonné <i>Podiatry I – coordinated systematic follow-up</i>	PcD - CHUV										
	Podologie II - campagne pieds élargie <i>Podiatry II – extended foot campaign</i>	PcD - SSP - CHUV						2014	2015			
	Stratégie et plan d'action relatif à l'accès aux soins pour les personnes diabétiques en situation socio-économique précaire <i>Strategy and action plan regarding access to care for diabetic patients of low socio-economic background</i>	PcD-SSP/SASH										

	Projects	Organisations in charge	2010	2011	2012	2013	2014	2015	2016	2017
	Transition pédiatrique <i>Paediatric transition</i>	PcD - CHUV								
	Prestations première ligne - mandat SSP PcD <i>Front line services – SSP PcD mandate</i>	PcD and partners							2016	
C TRAINING	Formation: compétences pour la prise en charge des NCD's - mandat SSP PcD <i>Training: skills for the management of NCDs – SSP PcD mandate</i>	PcD and partners							2016	
	Développement et diffusion des RPC <i>Development and circulation of clinical guidelines</i>	PcD - IUMSP- QualiCCare								
	Sensibilisation à l'éducation thérapeutique <i>Raising awareness on therapeutic education</i>	PcD - RS								
	Formation LLL diabétologie des diététiciennes <i>LLL training in diabetology for dieticians</i>	PcD - HES-SO						2015		
	Système d'équivalences glucidiques (table unifiée pour la Suisse) <i>Carbohydrate conversion system (standardised table for Switzerland)</i>	PcD - HES-SO						2015		
	Harmonisation de la communication et mise à jour des docDiab <i>Improved communication and docDiab update</i>	PcD							2016	
	Forums <i>Forums</i>	PcD - RS								
D COMMUNICATION	Communication - actions RP <i>Communication – PR actions</i>	PcD								
	Développement d'outils TIC pour l'éducation thérapeutique: projet DIS <i>Developing IT tools for therapeutic education: DIS project</i>	PcD, sponsors and physicians						2015	2016	
	Salon Planète Santé, appui aux campagnes de dépistage, aux séances d'information et autres mesures d'empowerment du patient <i>"Health planet" forum, supporting screening campaigns, information sessions and other patient empowerment measures</i>	PcD - ftc							2016	
	Réflexion PcD-AVD sur les objectifs du site internet et réorganisation de son contenu <i>PcD-AVD reflection regarding the objectives of the website and how to reorganise its content</i>	PcD-AVD								
E PRIMARY PREVENTION/ HEALTH PROMOTION	Projet Facebook Diabète Romandie <i>Facebook project for diabetes in Romandy</i>	PcD-AVD and partners							2016	
	Collaboration avec "ça marche! Bouger plus, manger mieux" <i>Collaboration with "ça marche!" project: "Move more, eat better"</i>	PcD - SSP - LS								
F PILOTING AND ASSESSMENT	Projet PASàPAS de remise en activité des personnes sédentaires, "ça marche" en collaboration avec les EP <i>"StepbyStep" project to help sedentary people to be more active, "ça marche" (it walks/it works) in collaboration with EPs</i>	PcD - SSP - LS					2014			
	Mutualisation du savoir: participation à divers groupes de travail CH, interc. et VD (comité QualiCCare) <i>Sharing knowledge: participation in various work groups at the national, inter-cantonal and cantonal (Vaud) levels (QualiCCare committee)</i>									
	Evaluation du PcD <i>PcD evaluation</i>	PcD - IUMSP					2014	2015	2016	
	Projets divers et pilotes (recueil, répertoire des professionnels de la santé, répertoire des formations ET, lunch diabète etc.) <i>Various projects and pilots (inventory, HCP directory, therapeutic education training directory, diabetes lunch, etc.)</i>	PcD								
	Organisation et pilotage du PcD <i>PcD organisation and piloting</i>	PcD							2016 ?	

PcD project list 17.05.2016

### **Appendix III Cantonal Diabetes Programme (abbreviation list)**

(Translated with permission of the Cantonal Diabetes Programme)

#### **Abbreviation list (Cantonal Diabetes Programme)**

AOVD:	Société d'ophtalmologie vaudoise – <i>Vaud Ophthalmologic Society</i>
AVD:	Association vaudoise du diabète – <i>Vaud Diabetes Association</i>
CHUV:	Centre hospitalier universitaire Vaudois – <i>Lausanne University Hospital</i>
DIS:	Projet DIS – <i>DIS Project</i>
EP:	Espace Prévention – <i>Health Promotion and Prevention</i>
ET:	Education thérapeutique – <i>Therapeutic Education</i>
Ftc:	Ftc communication SA – <i>Ftc Communication SA</i>
HES-SO:	Haute écoles spécialisée de suisse occidentale – <i>University of Applied Sciences and Arts Western Switzerland</i>
HOJG:	Hôpital ophtalmique Jules Gonin – <i>Jules Gonin Ophthalmologic Hospital</i>
IUMSP:	Institut universitaire de médecine sociale et préventive – <i>Institute of Social and Preventive Medicine</i>
LLL:	La Leche League – <i>La Leche League International</i>
LS:	Ligues de la santé – <i>Health Leagues</i>
NCD:	<i>Non-communicable disease</i>
PcD:	Programme cantonal diabète – <i>Cantonal Diabetes Programme</i>
PSHL:	Plateforme santé Haut-Léman – <i>Haut-Léman Health Platform</i>
RP:	Relation publique – <i>Public relations (PR)</i>
RPC:	Recommandations de pratique clinique – <i>Clinical guidelines</i>
RS:	Réseau santé – <i>Healthcare Network</i>
RSHL:	Réseau Santé Haut-Léman – <i>Haut-Léman Healthcare Network</i>
RSLC:	Réseau Santé La Côte – <i>La Côte Healthcare Network</i>
RSNB:	Réseau Santé Nord Broye – <i>Nord Broye Healthcare Network</i>
RSRL:	Réseau Santé Région Lausanne – <i>Lausanne Regional Healthcare Network</i>
SASH:	Service des assurances sociales et de l'hébergement – <i>Social Insurance and Accommodation Service</i>
SSP:	Service de la santé publique – <i>Public Health Service</i>
TIC:	Technologies d'information et de communication – <i>Information technology (IT)</i>

## Appendix IV Organisation of the Swiss healthcare system

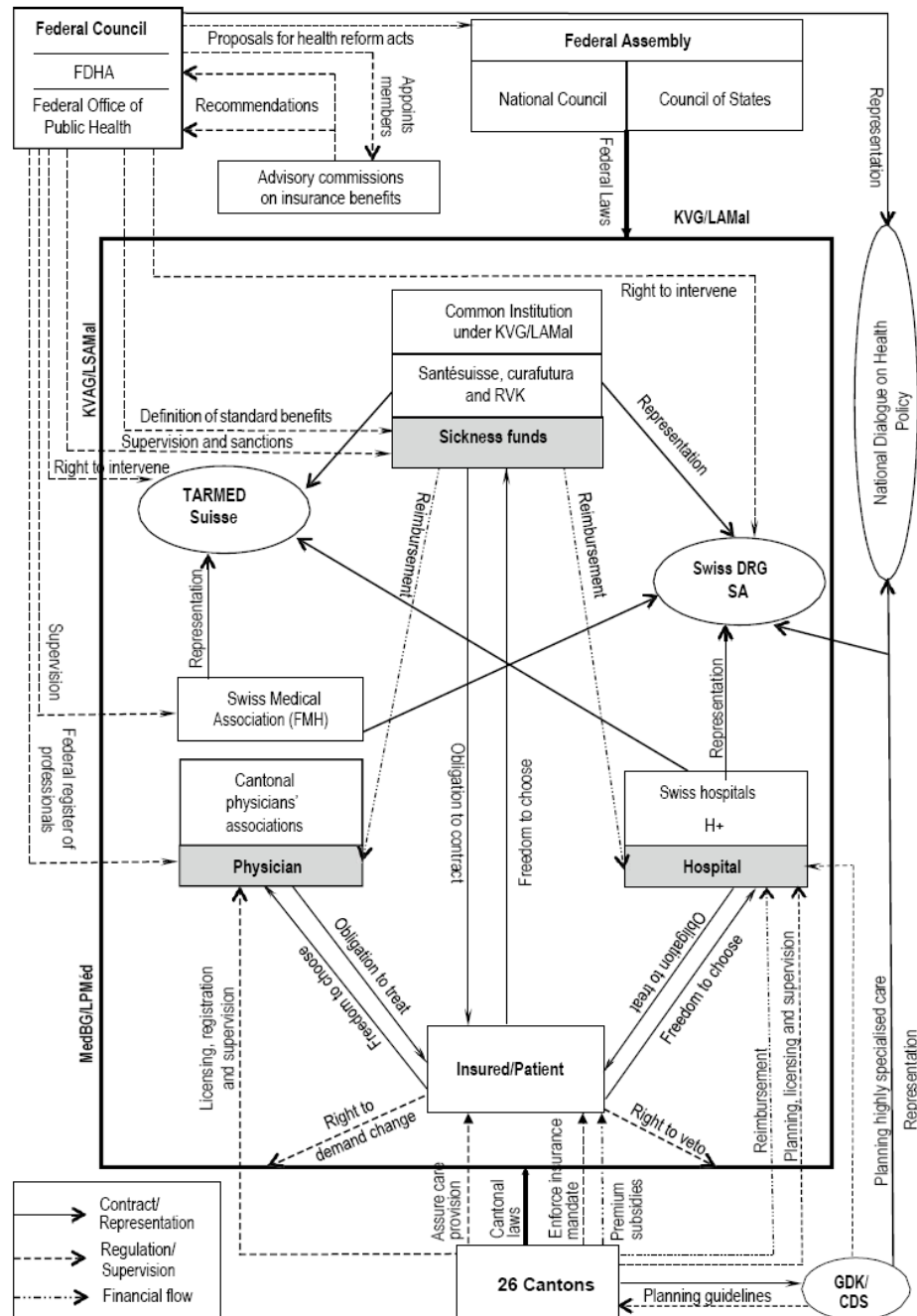


Figure IV-1 Organisation of Swiss healthcare system, adapted from de Pietro *et al.* (2015)

### **Abbreviation list (Organisation of the Swiss healthcare system)**

The following abbreviations are used in Figure IV-1. The list includes short explications of organisations mentioned:

FDHA:	Federal Department of Home Affairs
FMH	Swiss Medical Association FMH (Foederatio Medicorum Helveticorum)
GDK/CDS:	Conference of the Cantonal Ministers of Public Health
H+	Swiss Hospital Association H+
KVAG/LSAMal	Federal law on the supervision of mandatory health insurance
KVG/LAMal	Federal health insurance law
MedBG/LPMéd	Law on medical professions
RVK	Organisation of small and medium-sized health insurers RVK
Curafutura	Organisation of four major health insurance companies
Santésuisse	Leading branch organisation of Swiss health insurers
Swiss DRG SA	Swiss Diagnosis Related Groups for inpatient hospital services
TARMED Suisse	Swiss medical tariff system for outpatient medical services

## Appendix V Data extraction tool – Quantitative studies

Author, year, country, study design	Purpose/aim	Sample setting	Participants (receiver of intervention)	Healthcare professionals (deliverer of intervention)	Intervention, theoretical framework of intervention	Control
Follow-up				Primary outcome		Patient-reported outcomes, if available

## Appendix VI Data extraction tool – Qualitative studies

Extraction item	Details
Author, year, country	
Study design	
Purpose/aim	
Sample setting	
Participants (receiver of intervention)	
Healthcare professionals (deliverer of intervention)	
Data collection methods	
Ethical approval	
Participant eligibility criteria	
Sampling method	
Recruitment context	
Data analysis	
Themes	
Sub-themes	

## Appendix VII Examples of the synthesis of codes into themes/concepts to develop constructs

Excerpt from source study (examples of interpersonal relationship)	Codes	Themes/Concepts	Component of integration (synthetic construct)
“The high regard that participants had for the service was specifically linked to how the staff at the clinic related to patients; ... certainly they’re very supportive in what they do and they treat you as a person, not as a number, so all those are a definite plus.” (Hepworth <i>et al.</i> 2013, p.209)	High regard for clinic staff (HCPs) HCPs support patients HCPs recognise individual patients	Relationship of HCPs and patients in multidisciplinary care	<b>Interpersonal relationship</b> has been conceptualised as the interactions between patients and HCPs or peers that influence roles and positions in the learning experience of self-management education.
“I have stuck to all the rules that they have given me and that would never have happened if the whole system wasn’t in place ... working with the whole team I’ve been able to turn my liver and kidney functions back around.” (Hepworth <i>et al.</i> 2013, p.211)	Follow rules Collaborate with the team (“do what they say”) Didactic instruction	Collaboration with multidisciplinary diabetes care team	
“She [the peer educator] did know what she was talking about and she did know the pitfalls and what people would be facing, whereas the professional, you know the nurse, dealt with it from a professional point of view all the time but not from personally involved.” (Mandalia <i>et al.</i> 2014, p.640)	Feel understood by peers Receive information from HCP Interactions with peer and HCP	Peer support (identification with common experience)	



## **Appendix VIII Compendium of data collection tools**

All forms are presented in the translated English version.

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## **Appendix IX Interview topic guide – Patient**

### **About you:**

#### **Healthcare professionals involved in your diabetes care:**

1. Who is in charge of your diabetes management? (Probe: general practitioner, diabetes specialist, other)
2. Have you had consultations with other healthcare professionals? If yes, with whom? (Probe: diabetes specialist nurse, dietician, podiatrist, other)

#### **Reasons for participating in the self-management education programme:**

3. How did you hear about this programme (name of the programme) relating to self-management of diabetes?
4. What are the reasons why you wished to participate in this programme?
5. How did the members of your close family react on learning that you are participating in this programme?
6. How did your doctor or other healthcare professional react on learning that you are participating in this programme?

### **About self-management education:**

#### **Experiences with the current programme:**

1. Tell me about your experience with this kind of education.
2. In your opinion, what were the strong points of this educational programme?
3. In your opinion, what were the weak points of this educational programme?
4. In your opinion, in what way(s) could the education of patients about self-management be improved?

#### **Perception of the programme content:**

5. Was the education you received helpful for your needs in the daily self-management of diabetes? If yes, how? If not, why not?
6. How do you perceive that the programme content can be implemented in your everyday life?

#### **Active commitment to the management of your diabetes:**

7. Tell me about your relationship with the people who taught you.

8. Did this programme affect your commitment to self-manage your diabetes? If yes, how? If not, why not? (Probe: frequency of self-measurement, adaptation of the therapy to physical activity and diet, relaxation, other)?
9. How does this change translate into your daily management of diabetes? (Probe: in relation to communication with healthcare professionals, self-confidence, active participation, shared decision process, autonomy, other)
10. Have your healthcare professionals changed their attitudes towards you after your participation in the programme? If yes, how? If not, why not?

**Integration of the programme:**

11. How do you perceive that the education you have received is adapted to your needs in your daily self-management of diabetes? Could you give an example?
12. How could the educational programme be more consistent with your experiences of daily routine? Could you give an example?
13. How does the education you have received match the way your diabetes care is organised? Could you give an example?
14. How could the educational programme be more coherent with the other aspects of your diabetes care? Could you give an example?
15. How do you feel that the programme is influenced by the current care system? Could you give an example?

**Final question:**

16. Is there anything important which we have not covered and that you would like to share on this subject?

**Thank you for taking the time to answer our questions.**

## **Appendix X Interview topic guide – Healthcare professional**

### **About you:**

1. How many years of experience do you have in the education of patients and in your current professional role or function?
2. In how many programmes are you currently teaching? Are these similar or different programmes?
3. How would you define patient self-management education?

### **Reasons for participating in the self-management education programme:**

4. What reasons led you to enter the field of patient education?
5. What is your interest in being part of an interdisciplinary team?
6. What brings you satisfaction in your work (in relation to the programme)?

### **About diabetes self-management education:**

#### **Experiences with the programme:**

1. Tell me about your experience with this programme (name of the programme). How would you describe the programme in which you are currently teaching? (Probe: strong points, weak points, other)
2. What are the most important factors to support patients in their learning about self-management?

#### **Perception of the way the programme is currently running:**

3. How do you perceive that the programme in which you are currently teaching is adapted to the patients' needs?
4. In your opinion, what are the drivers and hurdles for running the programme?
5. In your opinion, what indicators allow you to say that the programme is running according to its aims?

### **About the integration of diabetes self-management education:**

1. Tell me about your relationship with the participants. How do you experience that they are participating in the programme? Could you give an example?
2. In your opinion, has teaching in this programme influenced your and other healthcare professionals' activities? If yes, how? If not, why not?
3. In your opinion, has participating in this programme influenced the commitment to exchange between healthcare professionals? If yes, how? If not, why not?

4. In your opinion, what changes could the patients make after programme participation?
5. If you follow up the participants, what changes do you observe in their activities after the programme?
6. Tell me about your interactions with the other members of the interdisciplinary team. How do you experience that the other team members are involved in the programme? (Probe: active participation, transfer of patients, management of care, other)
7. Could you give an example of an interdisciplinary collaboration in your context?
8. In your opinion, in what way(s) could interdisciplinary collaboration be improved? (Probe: team communication, interdisciplinary training, other)
9. In your opinion, in what way(s) could the patients' self-management support be improved? (Probe: healthcare network, recommendations for self-management practice, other)
10. Tell me about the integration of the programme into the patients' routine care. How do you experience that the programme is adapted to specific needs? (Probe: patients' needs, requirements of healthcare professionals, other)
11. How could the programme be coherently combined with the other aspects of patient self-management practice? (Probe: individual context, multi-morbidity, other)
12. Could you give an example of a programme adaptation to a specific situation?
13. In what way is the programme in which you are participating influenced by the care system? Could you give an example? (Probe: reimbursement, other)
14. How do you experience that the programme is set up in the care system?
15. What indicators allow you to say that the programme is well thought out to enhance its integration into patient routine care?

**Final question:**

16. Is there anything important which we have not covered and that you would like to share with us?

**Thank you for taking the time to answer our questions.**

## Appendix XI Documentary analysis

Table for documentary data extraction:

Items for data extraction	Details
Type of document: (e.g. leaflets, curricula, care protocols, guidelines, recommendations)	
Purpose of the document: (e.g. regulation, planning, information transfer)	
Content of document: (e.g. programme structure, process)	
Link to context: (e.g. interdisciplinary/intersectorial development, validation, review and update)	
People consulting these documents: (e.g. patients, healthcare professionals)	
Other aspects:	

## **Appendix XII Observation guide**

### **Observation guide of programme meetings:**

#### **Context/environment:**

- Date, place, time and duration of the meeting
- Documents given to participants
- Characteristics of participants
- Environment and layout of the meeting

#### **Programme objective:**

- Beginning of the meeting (e.g. who sets the agenda; how are the participants introduced to each other: are the roles and expectations clearly specified?)
- What topics are covered during the meeting? Are the topics clearly specified? (e.g. glycaemic monitoring, nutrition management, physical activity, concerns and psychosocial difficulties; behavioural interventions; promotion of health)

#### **Interactions during the meeting:**

- How do the participants interact during the meeting? (e.g. who is active, passive; who speaks?)
- How are participants encouraged to express their thoughts? (e.g. examples of personal experience, perceptions, time for questions, space to express other thoughts)
- How respond healthcare professionals to initiatives coming from patients? (e.g. encouragement, referring to peers and other resources)
- How respond participants to initiatives coming from peer educators and other peers? (e.g. showing interest/disinterest, respect/disrespect, expressing understanding)
- Who interrupts others? How are participants then encouraged to continue speaking?

(e.g. number of interruptions, moments of long pauses, laughter, apology, invite to continue speaking)

- Who chats together?

(e.g. patients, healthcare professionals with peer educators or other healthcare professionals)

- How does the meeting finish?

(e.g. summary of meeting by healthcare professionals, peer educators or patients, preview of next meeting, tasks to do between meetings, feedback signals)

- Other observations?

**Field notes (to be written immediately after the event):**

- During the observation, how did I feel about the participants and their interactions?
- What was my role in the interactions?
- How did my position influence the group interactions?
- Did the participants directly address comments to me during the observations?
- What was the main focus of my observations in this meeting?
- What do I want to observe in the next meeting?



### Appendix XIII Examples of coding indices with descriptions and development of sub-themes

Concepts/themes from literature review	Code descriptions	Excerpts (from Case A – patient interviews)	Final sub-themes (examples from Case A)
Learning strategy	Participation in self-management education and support: describes learning about disease and living with a chronic condition and sharing common issues	"I recognised myself in the circle of symptoms. I've always thought that was me but now recognise that it was the disease that made me tired". (A-1-16)	Sharing symptoms of chronic disease
Interactions with peers	Exchange of experience with peers (and/or other carer): describes interactions with other patients and peer educators	"I think ... precisely this experience, because it is often on this experience that we base our learning. It's the example ... someone says something and it, it speaks to me, and I put [it] in place." (A-1-19)	Finding meaning in experience
Positions of HCPs and patients in interactions	Positions and roles of HCPs and peer educators in self-management education: describes reflections on patient support from HCPs and peers	"Sometimes it's only a matter of terminology ... They rephrased but ... they didn't just tell us what our understanding was supposed to be. I think it was their way of being included ... [in the sharing]." (A-1-17)	Valuing experiential and professional expertise
Responsibility for disease management	Identification of reasons for programme participation: describes expectations, motivations and needs	"It is an interesting idea, because I think when you have diabetes, you have to take care of yourself and not put all of your trust in doctors. I'm not saying that doctors are bad. I'm saying that patients should take care of themselves." (A-1-19)	Recognising individual expectations
Local access to diabetes care	Accessing self-management education: describes about referral and community resources for patient support	"Having all the local contact details together in a separate booklet was really helpful, especially when looking for information such as where to go for more assistance and further support." (A-1-15)	Continuing with extended resources

## Appendix XIV Ethical approval – Canton of Vaud, Switzerland



COMMISSION CANTONALE  
D'ÉTHIQUE DE LA RECHERCHE  
SUR L'ÊTRE HUMAIN

**CER-VD**

Av. de Chailly 23  
1012 Lausanne

Madame Claudia Huber



Lausanne, le 21 juillet 2015  
Réf. AP/apl

### Décision de la Commission cantonale (VD) d'éthique de la recherche sur l'être humain (CER-VD)

No de protocole	237/15
Titre	Une étude de cas exploratoire de l'intégration de l'enseignement à l'autogestion du diabète de type 2 par des patients diabétiques et des soignants <b>Doctorat de Madame Claudia Huber, sciences infirmières</b>
Investigateur principal	Madame Claudia Huber
Date de soumission	01.06.2015 et 16.07.2015

#### I. Procédure

La CER-VD a statué en :

Procédure ordinaire	<input type="checkbox"/>	
Procédure simplifiée	<input checked="" type="checkbox"/>	23.06.2015
Décision présidentielle	<input checked="" type="checkbox"/>	21.07.2015

#### II. Décision

La décision concerne:	VD	PcD (programme cantonal diabète)
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☒ **Autorisation accordée**

Signification: L'étude peut commencer selon le plan de recherche accepté. Elle doit être menée dans le cadre des dispositions légales en vigueur.

**III. Classification**☒ **Projet de recherche au sens de l'ORH:**

recherche sur des personnes	Catégorie	<input checked="" type="checkbox"/> A	<input type="checkbox"/> B
réutilisation du matériel biologique ou des données personnelles liées à la santé			<input type="checkbox"/>
personnes décédées			<input type="checkbox"/>
embryons et des fœtus			<input type="checkbox"/>
avec rayonnements ionisants			<input type="checkbox"/>

**IV. Justifications de la décision/Remarques**

Pas de remarque

**V. Taxes et émoluments**

Déjà facturé

**VI. Voies de recours**

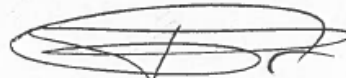
La présente décision peut faire l'objet d'un recours au Tribunal cantonal, Cour de droit administratif et public. L'acte de recours doit être déposé auprès du Tribunal cantonal dans les **30 jours** suivant la communication de la décision attaquée ; il doit être signé et indiquer les conclusions et motifs du recours. La décision attaquée est jointe au recours. Le cas échéant, ce dernier est accompagné de la procuration du mandataire.

**VII. Communication au requérant, et en plus à:**

Promoteur	<input type="checkbox"/>	Swissmedic	<input type="checkbox"/>	OFSP	<input type="checkbox"/>
Autres	<input checked="" type="checkbox"/>	Prof. Angus Forbes, FEND Chair in Clinical Diabetes Nursing, King's College London, <a href="mailto:Angus.forbes@kcl.ac.uk">Angus.forbes@kcl.ac.uk</a>			
		Prof. Jackie Sturt, Professor of Behavioural Medicine in Nursing King's College London, <a href="mailto:jackie.sturt@kcl.ac.uk">jackie.sturt@kcl.ac.uk</a>			
		Prof. Isabelle Peytremann Bridevaux, Unité d'évaluation des soins, IUMSP, route de la Corniche, 1010 Lausanne, <a href="mailto:isabelle.peytremann-bridevaux@chuv.ch">isabelle.peytremann-bridevaux@chuv.ch</a>			

**VIII. Composition de la Commission lors de la prise de décision**

Décision Présidentielle: Prof. André Pannatier, Vice-président



Prof. André Pannatier  
Vice-président

**Documents reçus le 16.07.2015 :**

Lettre d'accompagnement du 13.07.2015  
Lettre d'information destinée aux patients, version 3 du 02.07.2015  
Lettre d'information destinée aux soignants, version 3 du 02.07.2015  
Consentement éclairé écrit du patient, version 2 du 02.07.2015  
Consentement éclairé écrit du soignant, version 2 du 02.07.2015  
Texte d'annonce pour les patients, version 2 du 02.07.2015  
Synopsis du protocole de recherche, version 3 du 02.07.2015  
Formulaire de base du 02.07.2015  
Research Plan, version 3 du 02.07.2015

**La CER-VD s'aligne sur les principes ICH GCP****Obligations du requérant (promoteur ou investigateur):**

1. En cas de révision, les documents ainsi que la liste de vérification actualisée sont envoyés à la CER-VD sous forme papier et CD-Rom. La liste de vérification ne répertorie que les documents révisés;
2. Les événements indésirables graves, la fin ou l'arrêt prématuré d'un essai clinique et les modifications essentielles sont annoncés selon les dispositions légales en vigueur.
3. Le rapport final est envoyé à la CER-VD dans un délai d'un an au plus tard.
4. Les essais cliniques sont enregistrés dans un registre primaire de l'OMS ([WHO-Primärregister](#)) puis dans la banque de données complémentaire de la Confédération ([Swiss National Clinical Trials Portal \[SNCTP\]](#));
5. Pro memoria: Démarche pour la soumission des documents révisés:
  - Les documents révisés et la liste de vérification actualisée sont mis à disposition des commissions d'éthique sous forme digitale, et/ou d'un exemplaire papier.
  - La liste de vérifications répertorie uniquement les documents révisés.
  - Les modifications doivent être signalées dans les documents révisés.
  - Les documents révisés sont mis à disposition des autorités compétentes pour approbation.

## Appendix XV Ethical approval – King's College London

### Research Policy & Ethics

5th Franklin Wilkins Building  
(Waterloo Bridge Wing)  
Stamford Street  
London SE1 9NH  
Tel: 020 7848 4071/4070/3758  
Email: [rec@kcl.ac.uk](mailto:rec@kcl.ac.uk)  
[www.kcl.ac.uk/research/ethics](http://www.kcl.ac.uk/research/ethics)



Claudia Huber  
[Redacted]  
[Redacted]  
[Redacted]  
[Redacted]  
[Redacted]

1<sup>st</sup> September 2015

Dear Claudia,

**Re: Protocol number 237.15 – Integrated Self-Management Education for Type 2 Diabetes**

I am writing to acknowledge that you have obtained ethical approval from Swiss Ethics Commission of the Canton de Vaud to collect data in Switzerland for the above study. The study is being conducted for a PhD at King's College London. I understand that this approval has been granted in accordance with Swiss law. Therefore, you are not required to obtain dual ethical approval from King's College London.

If you should have any questions, please let me know.

Yours sincerely,

A handwritten signature in black ink, appearing to read "JPatterson".

James Patterson – Senior Research Ethics Officer

Cc: Angus Forbes

[www.kcl.ac.uk](http://www.kcl.ac.uk)

## **Appendix XVI Study information leaflet for healthcare professionals**

**Short title of the study:** Exploring the integration of self-management education in people with type 2 diabetes in routine care

**Researcher:** Claudia Huber, doctoral candidate, King's College London, Florence Nightingale Faculty of Nursing and Midwifery, London, claudia.huber@kcl.ac.uk

### **Search for study participants:**

As part of the study, we are looking for healthcare professionals who are currently teaching or who have recently taught in a programme of diabetes self-management education.

### **Aim of the study:**

To explore the experience and perception of healthcare professionals and patients with the integration of self-management, while they participate in a programme of diabetes self-management education. The objective is to understand how a certain type of programme influences the integration of diabetes self-management.

### **Procedure and duration:**

Participation in the study involves an interview which will consist of open questions so that you can express yourself freely. These questions will relate to the programme of self-management that you are currently or have recently been involved in and the way in which you experience this programme in your routine care delivery and in your interactions with the patients. This interview should last about one hour. It will be recorded with your agreement so that your words may be kept accurately. It can be conducted at a place of your convenience. You can interrupt the interview whenever you wish. You are free to refuse to answer certain questions.

### **Voluntary nature:**

Your participation in this study is voluntary and no compensation is provided for this study. But in participating, you are allowing the advancement of knowledge in the field of self-management education. All data will be treated confidentially.

Those who are interested in participating in the study and who fulfil the criteria mentioned above should leave their contact details with the researcher and an interview appointment will be arranged.

Please note that the personal details of those who will be contacted by telephone will be recorded. The personal details of those who ask for additional information and decide not to participate in the study will be destroyed immediately.

### **How to contact us:**

Claudia Huber (address, phone number and email)

## **Appendix XVII Study information letter for patients**

**Short title of the study:** Exploring the integration of self-management education in people with type 2 diabetes in routine care

**Researcher:** Claudia Huber, doctoral candidate, King's College London, Florence Nightingale Faculty of Nursing and Midwifery, London, claudia.huber@kcl.ac.uk

Please read this form carefully and do not hesitate to ask questions if there is anything you do not understand or if you would like additional information.

### **Invitation to study participants**

Dear Sir/Madam,

We are inviting you to participate in this study because you are currently following or have recently followed a programme of diabetes self-management education.

### **Aim and objective of the study**

This study aims to explore the experience and perception of patients and healthcare professionals with the integration of diabetes self-management education in routine care. The objective is to understand how following a certain type of programme influences the integration of diabetes self-management by the patients and their interactions with the healthcare professionals.

### **General information on the study**

This study is part of a doctoral research project of King's College London. This study is conducted in compliance with Swiss legislation and internationally recognised recommendations. Furthermore, it has been approved by the Cantonal Ethics Committee on Research Involving Humans of the Canton of Vaud on ... (date).

### **Voluntary nature of participation**

Your participation in this study is voluntary. Choosing not to take part will have no impact on your further medical follow-up. The same principle applies if you revoke your initial consent. You can therefore give up your participation at any time. You are not required to justify giving up your consent nor any potential withdrawal. If you do give up your consent, the data gathered up to this point will however continue to be used.

### **Procedure and duration**

We are asking you to participate in an interview with the researcher. This will be an individual interview which will consist of open questions so that you can express yourself freely. This interview should last about one hour. It will be recorded with your agreement so that your words may be kept accurately. All of your identifiable data will be removed during the interview's transcription and only de-identified data will be used for the analysis and sharing of results. You can interrupt the interview whenever you wish. The questions will relate to the programme of self-management education that you are following (or that you have recently followed) and to the way in which you experience this programme in your everyday self-management practice and in your interactions with

the healthcare professionals. You are free to refuse to answer certain questions. Your participation in this study is voluntary.

**Advantages for participants**

Your participation in this study will have no direct benefit for you. There is no compensation, but it may allow the advancement of knowledge in the field of self-management education. Your experience could lead to improved routes in diabetes self-management education programmes. By taking hold of these mechanisms, the healthcare professionals could be more attentive to maintaining a follow-up link with the patient and other healthcare professionals.

**Risks and inconveniences**

The main inconvenience is the time taken to participate in the interview. Some participants may feel uncomfortable about answering certain questions. If this occurs during the interview, we will end the interview and if it is required refer you with your consent to a healthcare professional who may be able to offer you personalised support.

**Data confidentiality**

The interview is confidential: all identifiable information concerning your first name, last name and personal context will be removed and recorded using a digital code. No proof of personal identification will be revealed, and all data will be stored securely in IT files protected by passwords and in locked folders: only the researcher of this study will have access to them.

The researcher carrying out the interview is required to respect professional confidentiality. No element of this interview will be communicated to your usual healthcare professional nor your regular healthcare team. Only encoded personal data is accessible for scientific evaluation purposes. The study supervisors may monitor the study's progression. In no case will your name be published in reports or publications resulting from this study.

The interview is recorded with your agreement in order to take into account the full content of your answers. The recordings will be kept until the end of the study and then destroyed.

**Written consent**

We will ask you to sign a consent form stipulating that you agree to participate in this study.

**How to contact us:**

Claudia Huber (address, phone number and email)



## Appendix XVIII Informed consent form

- Please read this form carefully.
- Do not hesitate to ask questions if any aspects are unclear to you or if you would like to ask for clarifications.

**Short title of the study:** Exploring the integration of self-management education in people with type 2 diabetes in routine care

**Researcher:** Claudia Huber, doctoral candidate, King's College London, Florence Nightingale Faculty of Nursing and Midwifery, London, [claudia.huber@kcl.ac.uk](mailto:claudia.huber@kcl.ac.uk)

### Participant:

First name and last name:

Date of birth:

☐ Male

☐ Female

- I declare that I have been informed, orally and in writing, by Claudia Huber, of the objectives and procedure of the study, the possible advantages and disadvantages as well as any potential risks.
- I certify that I have read and understood the written study information which was given to me about the aforementioned study, dated ... (date). I received satisfactory answers to the questions I asked in relation to my participation in this study. I will keep the written study information and receive a copy of my written consent declaration.
- I have had sufficient time to make my decision.
- I know that my personal data will not be passed on unless encoded. I accept that the relevant specialists of the authorised representatives of the study, the authorities and the ethics committees can, for scientific evaluation purposes, have access to this data, on the condition that its confidentiality is strictly guaranteed.
- I am taking part in this study voluntarily. I can, at any time and without having to give reasons, revoke my consent to participate in this study, without having to undergo any disadvantage.

Place, date:

Participant's signature:

**Researcher's statement:** I confirm by my signature that I have explained to this participant the nature, importance and scope of the study. I declare that I satisfy all obligations in relation to this study. If I were to become aware, at any time during the course of the study, of information that is likely to influence the consent of the participant, I pledge to inform the participant immediately.

Place, date:

Researcher's signature: